

CHALLENGING MEDICAL-LEGAL NORMS: THE ROLE OF AUTONOMY,  
CONFIDENTIALITY, AND PRIVACY IN PROTECTING INDIVIDUAL AND  
FAMILIAL GROUP RIGHTS IN GENETIC INFORMATION

Graeme T. Laurie LL.B. Ph.D.\*

## INTRODUCTION

Much ink has been spilled discussing the ramifications of genetic advances for individuals, communities, and society at large. A central concern has been the problem of regulating access to, and control of, genetic information that has been produced as a result of rapid progress in the fields of genetic research and genetic testing. To date, discussion has rightly focused on the uses to which genetic test results should be put, and, indeed, on the logically prior question of whether genetic information should be sought at all in certain circumstances. Debate has, however, tended to polarize the issues under scrutiny, setting the individual against the state or other interested parties such as insurers or employers. Moreover, from the perspective of the individual, the interests that have been identified as being at stake have centred on the autonomy of persons and the “right” that they have to control personal genetic information. While these are important starting points, it should be realized that the discourse barely has begun on the appropriateness of social, ethical, and legal responses to the novel challenges that are thrown up by such scientific advances. This article offers an alternative perspective on these challenges. In particular, three aspects of the debate are considered.

First, focus is placed on assessing the range of interests that are at stake when genetic information is generated, and in particular the interests of family members in shared familial genetic information are examined. It is the fact that genetic information relates to a group of persons and not simply to one individual that sets genetic information as a class apart from other forms of medical information. This requires us to consider the group dynamics of managing and controlling shared information, and the possible rights and interests that might flow from a “group” claim to familial data. These in turn must be seen in contra-distinction to the more traditional atomistic, autonomy-based approach, which focuses on the rights and interests of the individual from whom the genetic information initially has been obtained (the proband).

Second, the nature of the interests in issue must be examined to determine precisely

which factors, values, perceived benefits, and harms should be weighed in the balance when deciding how genetic information should be handled. This becomes particularly important if one adds the interests of family members to the equation. At first blush, the most obvious interest focuses on knowing genetic information, and, on this basis, arguments for a “right to know” are frequently founded. However, the potential existence of a “right not to know” genetic information, which may protect both personal and familial interests, also merits analysis. Only then can a proper assessment be made of the appropriateness of any use of the information in question. It is submitted that proper recognition of the interest in not knowing is urgently needed. Furthermore, in order properly to protect such an interest by legal or other means, a paradigm shift in medical-legal norms is required. This is revealed by an assessment of the role of more traditional concepts, such as autonomy and confidentiality in providing a suitable basis on which to found the claim not to know. As will be argued, these are wanting in the present context, and a viable alternative must be sought.

In the third and final section of this article a unique view of privacy is offered as a means of recognizing and protecting the full gamut of personal and familial interests surrounding genetic information, and most particularly, the interest in not knowing information in certain circumstances. The benefits of this concept are manifold, and its particular value for legislative purposes in designing ethically appropriate genetic privacy laws will be examined in the shadow of legislative proposals to protect genetic privacy to date.

## I. GENETIC INFORMATION: WHAT DO WE KNOW, AND WHAT DO WE NEED TO KNOW?

In seeking an appropriate legal response to advances in genetics, it is trite to observe that we require laws that are informed by ethical debate, that are morally sound, and that reflect as largely as possible our common societal values. These parameters must never be forgotten or

obscured in the legislative process, and they require, first and foremost, that we proceed in an informed manner whereby we are apprised of the functional utility of genetic information. The starting point then in deciding whether the promised benefits of genetic advances are truly desirable is to understand the limits of what information of this kind can allow us to do, and perhaps more importantly, what it cannot allow us to do.

#### A. The Uniqueness of Genetic Information (Individual v. Family)

Information is a unique entity. The same information can be used co-temporaneously by a large number of persons for a wide range of ends, and yet the essential character of that information may remain unchanged. Furthermore, a particular use by one person or group of persons does not preclude others from engaging in other uses of the information, for no two uses are mutually exclusive. Traditionally, when we have asked where the control of information should be located and how that control should be exercised, the answer has been that the person to whom the information belongs or to whom it relates should exercise that control; that is, the source of the information. In the genetic sphere, however, such an answer is simplistic and unsatisfactory.

As has been pointed out, genetic information differs from other forms of medical information because it pertains to a range of people and not solely to one individual. In this respect, it gives rise to special problems concerning how the information should be gathered, stored, accessed and used. While one might choose to locate control of a genetic sample with the person from whom it has been taken,<sup>1</sup> one cannot ignore the fact that genetic information derived from the sample also reveals information about the relatives of the sample source. And, these persons can base a claim to the information on precisely the same grounds as the source; namely, "I have a claim because it is about me." Moreover, the ends to which this information can be put may affect relatives in much the same way as they can affect the life of the person who has been tested. To locate the control of this information solely with the proband,

therefore, might seem to many to be an inadequate response to concerns about how information of this sort should be treated.

## B. The Distinction Between Family History and Test Results (Specific v. Abstract Knowledge)

It is sometimes claimed that a family history is simply genetic information in a different guise, and therefore that a genetic test result is no different to a known family history. Yet, family history is abstract knowledge that has been tainted by bad or failing memories, lack of accurate data about why someone has become ill or died, and by an absence of understanding about the pattern of disease in a family pedigree. In contrast, genetic test results can offer a high degree of specificity, both in terms of predicting the likelihood of disease in other family members and in terms of putting flesh on the bones of a suspicion that has heretofore been unconfirmed. Specific information brings with it a number of realities that can include a degree of “certainty” about future ill-health or even the mode and manner of one’s own death. These realities can impact an individual’s self-perception in ways that family history cannot, for, with the latter, one has the comfort of having lived with an abstract threat that has always manifested to someone else.

Specific knowledge of one’s own genetic constitution, especially when it is accompanied by knowledge of future ill-health, requires individuals to reassess themselves and their position within a family unit and to look with fresh eyes upon their family history which will have suddenly become very unfamiliar. Specificity of knowledge can deprive us of the ostrich’s ‘hole-in-the-sand’ which can sometimes serve as a valuable psychological coping mechanism.<sup>2</sup>

## C. The Perceived Utility of Tests (Introducing Other Interested Parties)

It is precisely because genetic testing is thought to offer a high degree of specificity in

determining future ill-health that genetic information is seen to have a “value” not only for a proband or his or her relatives, but also for parties outside the familial milieu. Insurers, employers, and researchers can find considerable utility in genetic information where test results might impact their own interests. It is apposite, however, to offer a word of caution on the perceived value of genetic information in this context.

Genetic diseases may have a variety of causes. On the one hand, monogenic diseases are caused by mutations in the genome that directly result in disease. These diseases can either be recessive or dominant. Recessive conditions such as cystic fibrosis or sickle cell anaemia are caused when an individual inherits two copies of a defective gene from his or her parents. If only one copy is inherited, then disease is not manifested, but the individual becomes an asymptomatic carrier for the condition. In contrast, dominant disorders are inherited when only one copy of a disease gene is passed on. Its influence overrides the effects of its twin “healthy” copy. In both cases, the predictability of disease in future generations is a relatively straight forward exercise. For a recessive disorder where both parents are carriers, there is a 25% risk in the case of each pregnancy that a child will be born affected, a 50% risk that a child will be born as a carrier and only a 25% chance that the child will inherit two copies of the healthy gene. For dominant disorders, the chances of having an affected child are 50% in each case. It is understandable that interested parties might place considerable store in test results, in light of such figures. However, it is of crucial importance also to consider other forms of genetic disease, which, in fact, represent by far the greater category of genetic diseases that affect individuals and families.

Polygenic disorders are caused by the interaction of two or more defective genes, and the chances of being affected are consequently more difficult to predict.<sup>3</sup> Moreover, these disorders are part of the wider class of multifactorial conditions that involve disease processes caused not only by genetic defects but also by the interaction of those genes with environmental factors, all of which can be operative in the onset of disease. Axiomatically, the predictability of

the onset of multifactorial conditions is considerably lower than that for monogenic conditions. The value of genetic test results for such conditions is consequently diminished. The obvious conclusion is that it is impossible to attach a uniform value to the practice of genetic testing for an entire range of conditions.<sup>4</sup>

But, even if third parties were to restrict their interests to monogenic disorders, the predictability value of testing is none the less affected by other considerations. Testing can only offer probabilities of onset of disease. Importantly, it cannot give any indications of when disease will arise, nor of the degree to which any one individual will be affected (and this can vary considerably as between individuals), nor can tests necessarily detect mutations for particular conditions. Accordingly, there can be a significant risk of false negatives.<sup>5</sup> All of these factors undermine the utility of genetic testing because they demonstrate that what is predictable is only predictable in a limited number of cases, which, in themselves, are further subject to a range of variables. Each of these factors can have a significant bearing on the outcome. Knowledge and certainty must, therefore, be seen as relative concepts.

#### D. What Is Genetic Information?

It becomes increasingly clear as more work is carried out on the human genome that a genetic component might have a factor to play in many disease processes, and not simply in those that have been classified to date as genetic. This may impact considerably on the subject matter of any legislation which is enacted to protect genetic information. A definition of this term that is too narrow might prove to be useless in protecting any interests at all, while an overly broad definition might, for example, encompass data used in important research, with the resultant risk that such work might be unduly hampered. Indeed, such a definition might include details of family history, if, as has been suggested above, a family history is thought to reveal familial genetic information.<sup>6</sup>

In recognition of these problems of definition the Task Force on Genetic Testing, a joint working group of the Department of Energy and the National Institutes of Health, has offered a working definition of genetic test information that seeks to strike a balance between protecting legitimate interests in test results while, at the same time, avoiding the conclusion that any kind of medical test is, in fact, a genetic test.<sup>7</sup> The definition restricts genetic testing to “processes which are carried out for the direct analysis of human DNA and other compounds such as RNA, chromosomes, proteins and certain metabolites, with a view to achieving a number of clearly identified end points; namely, the prediction of inherited disease, the detection of carrier status or the diagnosis of actual inherited disease.” This, then, can encompass not only the testing of individuals but also the screening of at-risk populations, and will include prenatal and antenatal screening and the testing of families with recognised histories of genetic disease.

By corollary, this also means that the contents of one’s medical file do not necessarily contain genetic information and that testing for certain conditions in which a genetic factor is operative, such as diabetes or ischaemic heart disease, will not be classified as genetic testing unless there is a high probability that the genetic form of the disease is at work. While it is the case that all human cellular material contains a complete copy of the genome (with the exception of the gametes), tests that do not involve the direct analysis of the DNA, but rather concern other traits of the cells, will not be deemed to be genetic tests. The Task Force specifically excludes certain testing from their definition, for example, tests conducted purely for research, tests for somatic mutations (compare heritable mutations), and tests for forensic purposes. On this basis, the genetic information that the Task Force would seek to protect would be restricted to information that arises from genetic tests falling within the definition, and would not be so broad as to cover abstract data about family history. A definition such as this would be an important starting point in developing specific genetic-related legislation. Of course, whether that exercise in itself is necessarily a good thing is another matter entirely, and will be discussed below.



## E. Lessons We Cannot (Currently) Learn from Genetic Information

A important rider to this discussion concerns the knowledge that genetic advances do not currently give us, except in a few, rare instances. Primarily, this is knowledge about how to treat or cure a genetic disorder for which a test has been developed. As the United Kingdom's Science and Technology Committee has pointed out,

“While genetics is likely eventually to transform medicine, it may take some while before treatments based on genetic knowledge become available...[i]n the short term, the most widespread use of medical genetics will be, as now, in diagnosis and screening”<sup>8</sup>.

This poses the dilemma of how we should respond to this limited knowledge. If the pursuit of better health is our goal, then we must ask whether, and how, this current knowledge can assist in achieving that goal. In the absence of therapies or cures, preparedness is often cited as a reason to seek out genetic knowledge. Certainly, one can better prepare for reproductive decisions in the light of proper information about genetic risks, and in the case of multifactorial conditions, lifestyle changes might minimize the health implications of carrying a defective gene. The achievement of psychological preparedness for the onset of future disease through the disclosure of risk is, however, by no means certain. Psychological health may be damaged, rather than improved, by such disclosures. This is explored further below. The lesson, however, is that we should not expect too much of this knowledge in our quest to improve health. To do so may mean that we achieve nothing more than the frustration our own efforts.

A final crucial lesson to be learned is that we cannot know all of the ends to which genetic information might be put. Illegitimate uses of this information, which result in harm, discrimination, and stigmatisation, must clearly be guarded against. Yet, the question of where the boundary lies between legitimate and illegitimate use, or indeed, between legitimate and illegitimate claims with respect to genetic information, is similarly not answered by the new

knowledge that genetic science gives us. We must, therefore, determine for ourselves where these limits are to be drawn. This article offers one model by which we may do so.

## II. THE INTERESTED PARTIES

It is through an examination of the respective interests which parties have in genetic information that we can understand the nature of potential problems. Such an analysis also serves to bring the issues within the rubric of a common language, which in turn allows us to compare and contrast various, and at times competing, claims with respect to genetic information.

An interest is here defined as a claim that a benefit can come to the party in question by recognizing that the party has a relationship with the subject of the interest; in this case, genetic information. The question of whether a party has an interest in genetic information is, of course, an evaluative matter. Integral to the notion of interest is the idea that it is in the party's interest to recognize the relationship with the genetic information. And, to do so, normally will lead to the conclusion that it is therefore in the party's interest to know, and to have access to the information, in question.<sup>9</sup> However, such an assumption should not go unchallenged in all circumstances, as is explained below.

### A. An Individual's Interest in Personal Genomic Information

It is axiomatic that a person who has been tested for one or more genetic conditions has a significant interest in knowing and determining what happens to the resulting information. Arguably, genetic information is “the most personal information of all”<sup>10</sup>. While it can be asserted that any form of personal health information is inherently part of the private sphere of an individual's life, genetic information has a unique relationship with the individual in many specific ways. For example, as Suter has noted,

“[w]hile contracting chicken pox has virtually no effect on identity, the knowledge that one carries a disease gene may influence one's self-perception and definition of "one's own concept of existence" in a way most infectious diseases do not”<sup>11</sup>.

Furthermore, and again unlike conventional health information, genetic information cannot be completely anonymised. It is a unique marker pointing the way to a single individual. As Gostin puts it:

Genomic data are qualitatively different from other health data because they are inherently linked to one person. While non-genetic descriptions of any given patient's disease and treatment could apply to many other individuals, genomic data are unique. But, although the ability to identify a named individual in a large population simply from genetic material is unlikely, the capacity of computers to search multiple data bases provides a potential for linking genomic information to that person. It follows that non-linked genomic data do not assure anonymity and that privacy and security safeguards must attach to any form of genetic material<sup>12</sup>.

Moreover, genetic information does not simply provide information about an individual's medical past, which is the case with most medical records. Genetic information also can furnish knowledge about an individual's medical future. This knowledge can be vague, in that we know only that the person has a certain percentage risk of developing disease, or it can be certain; we know that given time, disease will develop. Either way, such knowledge permits those who hold it to make judgments about the future life of the individual. Not all such persons will be the individual.

For these reasons, an individual has a very strong claim to control the circumstances in which this information is generated and to determine what happens to the information subsequently. In essence, persons have an interest in this information because it relates to them and can affect their lives in profound ways. As moral agents, their decisions regarding this information are entitled to respect.

## B. The Interest of Relatives in a Proband's Genetic Information

In an entirely unique way, exactly the same reasons specified above can be advanced by the blood relatives of a proband to claim an interest in genetic test results because a test result also will reveal information about them.<sup>13</sup> On this basis the “right to know” is frequently founded.<sup>14</sup> Yet, in one important respect, relatives stand in a very different position to a person who has sought out testing, for the latter has made a conscious decision to acquire the information in question, while this might not be true for relatives. We must, therefore, be alive to the possibility that family members might be surprised, or even loath, to learn of a relative's predisposition to a particular genetic condition, given the likelihood that they carry a similar risk. And yet, once such information exists questions of security, access, and control arise. Furthermore, if the individuals to whom the information relates do not agree on such issues, problems of weighing the competing interests in the balance must be addressed.<sup>15</sup>

The question of whether the interest of relatives is as strong as that of the proband is more difficult to answer. Certainly, the risk of more distant relatives being affected by a particular condition is reduced because of the different genetic influences to which they have been subjected compared with the proband.<sup>16</sup> Those relatives with the strongest interest of all are the first degree relatives of the person who has been tested. The interests of such relatives include those of the children of a proband who might want to know whether they have any risk of disease that might affect themselves or their progeny. Siblings, too, have a strong interest in each other's test results given their common parentage. A further complicating factor is the potential claims of non blood-related relatives such as spouses, whose reproductive decisions can be profoundly affected if they are denied access to genetic information that might indicate the presence of disease within their partner's family.

Finally, it is important to stress that, even if test results show no risk of disease, it should not be presumed that individuals will be happy to surrender control of genetic information. Relatives retain an interest in each other's genetic information even if it reveals nothing sinister. The information is intimately connected with their private sphere and their sense of self and therefore to disrespect the information is to disrespect the persons concerned. Moreover, it should not be thought that accuracy of information is in any way a prerequisite to discrimination or stigmatization at the hands of third parties.<sup>17</sup>

From the above it is clear that conflict will arise when the proband wishes to keep test results secure and family members wish to know them. That is, when the individual wishes to keep the data private and the family wish to invade that private sphere, or perhaps, become part of that private sphere. The converse is, of course, also true. For, conflict can arise when the proband is willing to permit access to genetic information, for example, to third parties outside the family, yet relatives are unwilling to relinquish control of these familial data. Here family privacy might be in jeopardy. Moreover, relatives might be unwilling to receive such data into their own private sphere when they have previously been in ignorance, given the implications this knowledge might have for their future lives. Here the privacy of the relatives might be invaded by unsolicited disclosures of information to them.

### *1. The Individual and the Family: An Interest in not Knowing?*

The question arises of whether individuals - either a proband or his or her relatives - have an interest in not knowing test results. For example, a proband might agree to be tested but then change his or her mind. Equally, relatives might be approached by a proband willing to reveal test results but they might refuse to accept the information. On what basis might individuals have an interest in not knowing information?

It is frequently argued that knowledge of genetic information can bring many benefits to individuals. If a cure or therapy is available, then it can be sought and ill health may be averted. Yet, even if a cure or therapy is not available, knowledge can nevertheless serve several ends. For example, because multifactorial conditions are by definition affected by many influences including the non genetic, knowledge of a predisposition to such a condition can provide individuals with the opportunity to change aspects of their lifestyle. This can in turn influence the onset of disease.<sup>18</sup> Moreover, it has been argued that, with knowledge, comes preparedness for the risk of developing a disease at a later stage in life.<sup>19</sup> Similarly, the discovery of disease or predisposition to disease means that any reproductive decision that is taken thereafter will be an informed one. Unfortunately, such arguments all suffer from one fundamental weakness: they presume that only benefit can result from knowledge. This is not necessarily so.

The availability of a cure or a therapy carries with it the certainty that disclosure can avert harm uncontroversially, or at least minimize it considerably.<sup>20</sup> For a person to whom such a disclosure is made this can only be seen as a good thing. If, however, disclosure is made to avoid an ancillary harm, such as psychological upset, then there is less of a guarantee that the harm in question will, *de facto*, be avoided. Evidence exists from empirical studies that both supports<sup>21</sup> and refutes<sup>22</sup> the benefits of disclosure to facilitate preparedness. Thus, it is entirely possible that individuals might be loath to learn of a relative's genetic status because of the implications this knowledge can have for their own well-being. Indeed, the Danish Council of Ethics has warned of the risk of “morbidity”: the notion of falling victim to some inescapable fate through knowledge about risk of disease.<sup>23</sup>

The possible adverse effects of knowledge of genetic predisposition have been well documented by Hoffman and Wulfsberg.<sup>24</sup> They cite three examples of child screening programmes in Sweden, the United States and Wales involving respectively, Alpha<sub>1</sub> -antitrypsin deficiency,<sup>25</sup> Cystic Fibrosis,<sup>26</sup> and Duchenne's muscular dystrophy.<sup>27</sup>

In 1972, the Swedish government initiated a nationwide screening program of newborns. As part of the program parents were (1) told whether the child had alpha<sub>1</sub>-antitrypsin deficiency, (2) counselled to protect the child from environmental factors such as smoking or high dense-particle atmospheres, which could exacerbate the child's problems, and (3) followed to determine the psychological impact of the information. Follow-up studies showed that more than half of the families with affected children suffered adverse psychological consequences, some of which continued for five to seven years. Moreover, there was little evidence of reduction in smoking among parents of affected children. Indeed, in some cases, an increase was noted. This led directly to the abandonment of the program by the Swedish government in 1974.<sup>28</sup>

In like manner, Hoffman and Wulfsberg note that Cystic Fibrosis screening programmes in the United States, which commenced as early as 1968, were abandoned because “many people think (even in cases where there is a familial risk for the disease) that early detection has no value and may, in fact, cause the family significant psychological distress prior to the time when the individual might become symptomatic”<sup>29</sup>. For these reasons the authors assert that the United States has not instituted a programme of screening newborns for Duchenne's muscular dystrophy, unlike Wales in the United Kingdom, where such a programme has run since 1990.<sup>30</sup>

Similar evidence is available for adults. Kevles has noted, citing several studies, that, “[t]he revelation of genetic hazard has been observed to result not only in repression but in anxiety, depression, and a sense of stigmatisation”.<sup>31</sup> Most recently, Almqvist et al. have found in an international study that the suicide rate among persons given a positive genetic test result for Huntington disease was 10 times higher than the United States average.<sup>32</sup> While this rate is no greater than that for the symptomatic Huntington disease population (nor indeed, is it vastly greater than the rate for persons with other debilitating and progressive diseases), it is significant that the survey primarily focused on the two years after test results were given. This would tend to indicate that the deaths were more directly related to the disclosure of the genetic information, rather than to some other factors, such as the onset of disease itself.<sup>33</sup>

Finally, it has even been observed that confirmation of one's status as a non affected person also can have adverse psychological effects. Huggins et al<sup>34</sup> and Wexler<sup>35</sup> have carried out studies in families affected by genetic disease that show “[m]any may suffer ‘survivor guilt’, particularly characteristic of wartime soldiers who live while their buddies are killed”.<sup>36</sup>

The possibility that any or all of these forms of harm can result means that individuals can cite a strong interest in not knowing genetic information about themselves.<sup>37</sup> However, one should not imagine that potential harm is the only reason for claiming an interest in not knowing. The question of respect also arises. To disclose genetic information to someone who has not expressed a desire to know may be disrespectful in two ways. First, if the individual has specifically stated they do not wish to know the information, then it is an affront to them as moral chooser to furnish the information nevertheless. Second, even if no such wish has been expressed, then it can be offensive to provide information in the absence of a justified reason for doing so. While no tangible harm might result from disclosure, the fact that the individual's private sphere is invaded with such information can be problematic. For example, it was stated in the preamble to the World Medical Association Declaration on the Human Genome Project that “[t]his area of scientific progress will profoundly affect the lives of present and future members of society, bringing into question the very identity of the human individual and intruding upon the snail's pace of evolution in a decisive and probably irreversible manner”.<sup>38</sup>

The implications these advances have for personal privacy are extremely far-reaching. To discover that one is likely to develop a debilitating condition in later life or that one might pass on such a condition to one's children can be a devastating and profound experience. Exposure to such knowledge can challenge notions of self-identity and alter considerably one's self-perception.<sup>39</sup> It requires individuals to take on board information which then cannot be unknown. The knowledge becomes a factor that will necessarily become part of many future life decisions of the individual. Individuals are coerced into self-reflection and forced to evaluate and reevaluate themselves. While it might be argued that it is in the individual's best interests to



know the information, this is to make an evaluative judgement which, to be justified, must surely weigh in the balance the possibility that disclosure might be unwanted or harmful in certain circumstances. To presume that individuals will always and necessarily wish to know familial genetic information is not only to ignore these possible adverse consequences, but it is also to disrespect such persons, for such a presumption disregards the individuality of subjects and subjugates them to a view of life which is not their own.

For all of these reasons it is submitted that both the proband and his or her relatives could have an interest in not knowing genetic information. However, the recognition of this interest complicates matters considerably. The various claims require close scrutiny, especially given that the resolution of the matter also will have implications for family members further down the genetic line. In order to conduct this scrutiny adequately, it is necessary to consider the key principles, values, and factors that are of relevance in resolving conflict dynamics in the medical-legal sphere.

### III. WESTERN PRINCIPLES AND VALUES: A BRIEF ANTHOLOGY

#### A. Principles of Ethics

The so-called “four principles of ethics” have significantly influenced much of western thinking and action, particularly in the medical-legal sphere. These four principles are autonomy, beneficence, nonmaleficence and justice.<sup>40</sup> Autonomy refers to a state of moral independence, and an autonomous individual is one who is a “moral chooser”.<sup>41</sup> The principle of respect for patient autonomy is fundamental to good medical practice and is the cornerstone of many ethical and legal requirements concerning the way in which health care professionals treat their patients. Among other things, the principle requires that patients be consulted about health care provision, that their consent be sought to proceed with medical interventions, and that their wishes concerning treatment be respected, even when such wishes run counter to the advice or

wishes of health care professionals. This extends to respect for the patients' wishes about their personal health information. Beneficence and nonmaleficence prescribe, respectively, that one should strive where possible to bring benefit to individuals and that, contemporaneously, one should endeavour at all times to minimize harm to them and others. Justice requires that comparable cases be treated alike and that no unjustifiable decisions are made that prejudice one individual or group over another on irrelevant or unjustified grounds.

## B. Confidentiality

Confidentiality is characterized by a relationship involving two or more individuals one or more of whom has undertaken, explicitly or implicitly, not to reveal to third parties information concerning the other individual in the relationship. It is widely accepted that health care professionals owe a duty of confidence to their patients and that only rarely should disclosure without patient consent be made. While exceptions to the duty exist, in practice no breach is made lightly or without good cause. Confidentiality is the duty of the health care professional and the right of the patient.

## C. Privacy

The definition of privacy offered in this article and the justification for its value will be argued presently. More generally, privacy is an interest that is premised on setting the “private” - which is bound up inherently with the personal - in contradistinction to the “public”. The maintenance of a public/private divide, and the location of certain personal attributes within the latter and therefore out of the reach of the former, is commonly taken as a “good”. It should be clear that certain interests may be common to privacy, confidentiality, and autonomy, and may be protected to varying degrees by each. This is especially true in the context of personal information.

#### D. Public Interest

Public interest is an amorphous concept that has a role to play in both ethics and law. It acts as a safeguard equally for individual and collective interests, but suffers from a lack of precise definition. It is open to abuse as a result. Nevertheless, the concept reflects many important values and must be considered in this debate. When public interest enters the equation it is usually weighed in the balance with another public interest. For example, the public interest in disclosure compared to the public interest in maintaining confidences generally. In the context of public interest, community interests and values are at stake, and, as such, necessarily and frequently subsume private interests within their scope.

#### E. Additional Factors

In addition to the above, there are several factors that must be considered when trying to resolve complex issues surrounding genetic information. These are not only highly relevant but context specific and can be invoked - alone or in combination - in particular situations to assist in making the strongest argument for the most appropriate outcome. These factors are listed below.

##### 1. *The Availability of a Therapy or Cure*

If death or disease can be avoided incontrovertibly, or if the effects of disease can be substantially diminished, then it is trite that very strong arguments must be advanced to prevent disclosure of genetic information to those likely to be affected, especially in the absence of some other means of preventing harm. If, however, nothing can be done to prevent the onset of genetic disease or to alleviate suffering, then the argument for disclosure is accordingly weakened.

##### 2. *The Severity of the Condition and Likelihood of Onset*

A fatal condition intuitively calls for action if death can be prevented. In contrast, a mild condition for which nothing can be done makes arguing for disclosure more difficult. In like manner, a 50% risk of developing a genetic condition, which lies with a first degree relative, is more compelling than a 1% or 2% risk to unidentified third cousins.

### 3. *The Nature of Genetic Disease*

The affliction of one individual with genetic disease does not pose any direct threat to any other living human being. In this respect, genetic disease is very different to many other diseases. Also, with recessive disorders that render people asymptomatic carriers, there is additionally no threat to the health of the carrier. Only future progeny might be affected. Facts such as this can have a bearing on how one views particular complex scenarios.<sup>42</sup>

### 4. *The Nature of Genetic Testing*

The point already has been made that predictive genetic testing (and family history) are imprecise tools for assessing future risk. Thus, it is important to appreciate that any trade in information is trade in further uncertainty. People may be alerted to a possibility, but they cannot be apprised of a medical certainty in respect of their own health without undertaking further steps, such as additional testing. If there is good reason to suspect that such further steps will not be taken, then there is good reason to reflect seriously on any decision to disclose information at all.

### 5. *The Nature of the Request*

If individuals are asked to disclose or receive genetic information, then the specific nature of the request might have an influence on the outcome one would recommend. For example, if an individual is asked simply to take part in linkage tests to determine a relative's particular risk (for procreative purposes) and the tested individual receives guarantees that she or he will not be given the test results, then such an altruistic gesture is unlikely to conflict in any way with that individual's interests. Compare this with an unexpected advance from a health care professional

or relative to disclose a 50% chance of developing a late onset condition in the future. In the former example, the individual is not being asked to take on board any information about himself or herself, while in the latter they are placed in a position where they have no other option but to do so.

#### 6. *The Views and Likely Reaction of the Disclosee*

Evidence of how individuals might react to information about their genetic make-up can be of considerable assistance in determining whether a disclosure should be made. Clearly, of most value is evidence that the individual has specifically requested to know or not to know the information in question. This is an expression of autonomy and as such should be respected where possible.

### IV. SCENARIO

The following scenario is offered to demonstrate the problems that can arise when the factors, principles, and values discussed above are brought to bear on practical situations. The scenario will be considered from the perspective of the three central stalwarths of medical law and ethics; namely, autonomy, confidentiality, and privacy. It will be argued that the first two of these fail to protect adequately the interests at stake, and an argument will be put in defense of a particular conception of privacy as a means to recognize and protect the interests in question.

#### A. Recognizing a Right Not to Know?

BRCA1 is the gene responsible for between five and ten percent of female breast cancers. It was discovered in 1994 and is known to be ten times longer than most human genes.<sup>43</sup> This fact means that the likelihood of mutations is increased and this in turn has implications for the efficacy of test kits designed to identify the gene, for they cannot detect all mutations. There

is a high risk of secondary cancers associated with this disease, but early detection and radical intervention in the form of mastectomy can reduce this risk. Preventative measures, also in the form of mastectomies, can reduce the instances of disease.<sup>44</sup> The condition is also thought to be multifactorial, further complicating matters.

Nicola is aware of a history of breast cancer in her family. Her mother, her great-grandmother, and one of her aunts died from the disease. Nicola has a sister, Nadia, and three female cousins, Norma, Romana, and Elvira. She does not know the extent to which these relatives are aware of the pattern of disease in the family. Recently, Nicola discovered a lump in her breast which has been diagnosed as malignant. She is concerned that the BRCA1 gene runs in her family and that her sister and cousins are at risk. Nicola's physician has advised a mastectomy and has strongly urged her to contact her relatives to arrange testing. Should she approach her sister and cousins with the news of her own disease and urge them to seek medical advice? She is aware, for example, that Nadia is phobic about operations and that Elvira is prone to bouts of depression.

## V. Shifting Paradigms: The Efficacy of Autonomy, Confidentiality, and Privacy in Meeting Challenges posed by Genetic Advances

In this section, we explore the nature and content of the ethical and legal principles of autonomy and confidentiality to discern what assistance, if any, they offer in the resolution of this dilemma. In the next section, the conclusions of this section are contrasted with the solution proposed by the author's concept of privacy.

### A. The Merits of Existing Paradigms: Autonomy

The term autonomy is derived from the Greek words *autos* ("self") and *nomos* ("law" or "rule"). While there is no unifying definition of the principle of autonomy from the philosophical or

ethical perspective,<sup>45</sup> certain core elements can be identified that provide a workable model of autonomy for use in the health care setting.

First, the idea of choice is central to the principle of respect for autonomy.<sup>46</sup> To be respected as an autonomous person is to have one's choices respected. Second, crucial to this respect is noninterference. In order to make one's own choices - that is, for those choices to be autonomous - one must be unrestrained by unwarranted interference by others.<sup>47</sup> Finally, bound up with all of this is possession of the capacity to make one's own choices.<sup>48</sup> Although autonomy is concerned with choice and the exercise of that choice in relation to life decisions, realistically it must be accepted that no person can control, at all times, all aspects of his or her life.<sup>49</sup> It is only necessary that a certain degree of autonomy is reached and that capacity to make a choice is present in relation to the choice which must be taken. The standard that is required in practical terms is always a question to be answered with reference to the facts and circumstances of each case.<sup>50</sup> Rather, what is important is that autonomy and autonomous choices be respected. This is embodied in law in most western jurisdictions in ways that do not require repetition here.<sup>51</sup>

It should not be thought, however, that the principle of respect for autonomy and the other ethical principles discussed above always function harmoniously. Indeed, it is easy to imagine situations where an individual might wish to exercise his or her autonomy in a manner that might interfere with the autonomy of others and/or cause them harm and/or treat them unfairly. As Beauchamp and Childress point out,

“Respect for autonomy . . . has only prima facie standing and can be overridden by competing moral considerations. Typical examples are the following: If our choices endanger the public health, potentially harm innocent others, or require a scarce resource for which no funds are available, others can justifiably restrict our exercises of autonomy. The justification must, however, rest on some competing and overriding moral principles”.<sup>52</sup>

Thus, just as the principles of nonmaleficence, beneficence, and justice can serve to accord respect to individuals and their autonomy, the same principles can be used to impose restrictions on individual action and autonomy if this conflicts with other third party interests. Ethical principles provide us with a framework of moral reference within which to analyze human behaviour and human interaction. Only in a very crude way, however, do they provide us with the means of resolving conflict.

### *1. Autonomy and Genetic Information*

The relevance to genetic information of what has been said above should be obvious. It has already been argued that aspects of the self such as the body and personal information require respect under the principle of autonomy. The principle also dictates that individuals deserve respect concerning the choices they make about what happens to their bodies and their personal information. Thus, the principle prescribes that choices concerning genetic information are equally deserving of respect. Several problems, however, become immediately apparent. First, given that genetic information concerns many individuals in a family, how can the principle of autonomy help us to resolve conflicts that arise about the control and use of the information? For example, if Patient A is tested and found to be a carrier of cystic fibrosis but wishes to keep this to himself, does his pregnant sister nonetheless have a right to the information so that she can make an appropriate and autonomous choice about her pregnancy? In other words, what is to be done when two autonomies conflict?

Second, it was noted earlier that there exist certain fundamental criteria that are necessary to be an autonomous individual. Central to the principle of autonomy is choice. In particular, choices must be taken free from interference and by someone who has the capacity to make those choices. Fundamental to such choices is knowledge. One cannot choose in a meaningful sense if one is not informed of the parameters within which one must choose. This is why informed consent is crucial to ethically and legally acceptable health care. However, in the



context of genetics this may be problematic. For, in many circumstances, the problems surrounding genetic information are precisely concerned with the absence of knowledge: this is the basis of the claim to respect the interest in not knowing genetic information. The choice, if there is one, is whether to receive or not to receive information about oneself. This is problematic for the concept of autonomy because it is difficult to see how one can exercise meaningfully a choice not to know unless one has a certain degree of knowledge that there is something to know. Of course, an obvious practical solution would be to approach the individual and ask, “do you want to know this information?”, but as Wertz and Fletcher have pointed out, “[t]here is no way. . . to exercise the choice of not knowing, because in the very process of asking, ‘Do you want to know whether you are at risk. . .?’ the geneticist has already made the essence of the information known”.<sup>53</sup>

This is not to say that one cannot simply state “I wish to know no information about my genetic make-up whatsoever”, nor is it to suggest that such a wish should not be respected. However, the requirement that autonomous choices be informed choices tends to imply that the credibility of an uninformed choice is more easily questioned. It leaves it open to be argued that actual knowledge about circumstances might nevertheless affect the chooser who might choose differently if furnished with relevant information. Alternatively, the situation might be seen as analogous to the problem of the incapax. Individuals who are incapax cannot choose for themselves and so must have choices made for them. In the same way, individuals who are ignorant of genetic information might be seen as a pseudo-incapax and therefore it might be assumed that it is legitimate to make choices about the genetic information on their behalf, including the choice whether to know. Choices for the incapax are often made in the person’s best interests. It is far from clear, however, how one would determine an individual’s best interests concerning genetic information, given that the passing on of knowledge itself can be harmful.<sup>54</sup>

Applying an autonomy perspective to our scenario reveals how these limitations prove problematic in the context of deciding what is the best thing to do with genetic information. Nicola must determine whether to approach her relatives with a possible index of genetic risk in the absence of any views about her relatives wishes. What guidance might be offered by the principle of autonomy?

At first blush, one might assume that because no views have been expressed by the relatives the principle of autonomy is unhelpful. In like manner, the principles of nonmaleficence and beneficence also would appear unhelpful because of the nature of the condition and the circumstances of the family. These principles require that harm should be avoided and benefit conferred wherever possible. It is not clear, however, whether this could be achieved by the subject of our scenario by disclosing information about her condition and the risk to relatives. As has been argued above, harm can result from the mere fact of disclosure and the personal circumstances of two of the relatives would tend to indicate that psychological trauma is probable. Also, it is important to consider the nature of the treatment that is offered. Mastectomy is a very traumatic and potentially psychologically devastating operation. The sequelae can include altered perception of self-image and feelings of loss of identity. The preference for some women might be not to have the operation. This is likely to be true of Nadia who is phobic about surgery. Furthermore, even if testing proves to be negative, exposure to the knowledge of increased risk can heighten concerns about future ill health. Testing and counselling might not allay such fears, especially in someone such as Elvira who is depressive. These factors mean that Nicola should consider very seriously whether or not to disclose the information.

Yet, the perceived utility of autonomy-based arguments extends beyond circumstances in which a meaningful choice is within the grasp of an individual. For, even in cases where no choice has been made or where no meaningful choice is possible for want of information, autonomy is frequently advanced as a reason to put individuals in a position whereby they can

choose. Indeed, the facilitation of autonomous choices is a generally given good in contemporary health care.<sup>55</sup> However, it is important to distinguish between cases in which the physician-patient alliance has been established at the behest of the patient, and those in which an individual is approached by a physician, or some other third party, with information that is perceived to be of benefit to the individual's future health. In the former case, an alliance has been established wherein the goals of the union have been agreed by the parties, and when the promotion of the patient's health (and autonomy) is one of those goals. In the latter case, there is no mutually agreed alliance, and unilateral efforts to "optimize [someone else's] future health"<sup>56</sup> are ontologically and ethically different. Indeed, Malm has gone so far as to argue in the context of screening that, while a recommended treatment for a patient should be justified on the "preponderance of the evidence" as embodying a benefit, in the case of preventive medicine "the evidence must show it to be beyond reasonable doubt that the recommended procedure will benefit the patient on balance."<sup>57</sup>

This is not, however, a well accepted view. The preferred view is that autonomy should not only be respected, but sought out where possible. Thus, in our scenario, Nicola might be drawn on an autonomy analysis to disclose her family information to her relatives, in spite of the risks, in order to allow her relatives to choose for themselves what they wish to do.

For all of these reasons, it is submitted that the principle of autonomy is particularly unhelpful in addressing the question of an interest not to know. Nicola cannot simply approach her relatives to ask if they would like to know, because this in itself immediately compromises the interest in not knowing. If she treats them as incapax, she then must consider what is in their best interests, but this is not easily discernible on the facts. Nor, indeed, does it have anything to do with the autonomy of her relatives, but rather their perceived incapacity. Finally, if she seeks to facilitate their autonomy, then disclosure is likely, because the bias is to allow persons to decide for themselves by knowing the options which are available. This, however, ignores the fact that the interest at stake is one about whether to receive knowledge at all.

All of this would tend to indicate that the basis for a claim not to know information cannot be the principle of autonomy alone.

## B. The Merits of Existing Paradigms: Confidentiality

Confidentiality is concerned with security of information. To be precise, it is concerned with the security of confidential information. To be confidential, information must be in a state of limited access from individuals, groups, bodies, and institutions generally.<sup>58</sup> The nature of the confidential relationship has been described above. Most particularly, it is accepted almost unquestionably that health care professionals owe a duty of confidence to their patients and that only exceptionally should disclosure without consent be made.<sup>59</sup>

It is trite, therefore, to confirm that the woman who has been diagnosed with breast cancer in our scenario is owed a duty of confidence by her health care professional. This entitles her to decide whether and how the information, which is the object of the duty, should be disclosed to others. However, in the case of her relatives, it would be possible for the health care professional to justify disclosing the information to them even without the patient's consent, because the duty of confidentiality is not absolute, and certain exceptions are admitted, including actions to prevent harm to third parties.<sup>60</sup> Indeed, a considerable and far-reaching discretion to disclose on such grounds is afforded to health care professionals. Yet, this is not our problem in the scenario. Nicola is willing to tell her relatives about her condition; our problem is that it is not clear that she should do so. What is clear, however, is that she cannot herself breach a duty that is owed to her by another. If she decides to disclose her condition to her family there could be no question of a breach of the duty of confidence. Thus, for her disclosure to amount to a breach of confidence, it must be seen to be an invasion of someone else's right and a breach of her duty to maintain confidentiality. Can the family dynamic envisaged by our scenario fit into such a rubric?

The first matter to determine is the circumstances in which a duty of confidence arises as between two parties. Legally,<sup>61</sup> professionally,<sup>62</sup> and ethically,<sup>63</sup> health care professionals owe duties of confidentiality to their patients. While the sources of this duty in law are many and varied<sup>64</sup>, in each case the duty arises with respect to the specific relationship that the professional has with patients, *qua* patients, and it is not thought to be the case that legal duties arise merely by virtue of the fact that an individual comes into possession of personal information about another.<sup>65</sup> Thus, absent some specific customary or professional, contractual or impliedly contractual relationship,<sup>66</sup> a duty to maintain confidences is unlikely to arise.<sup>67</sup> This would suggest that, in our scenario, no duty of confidentiality is owed to the relatives of Nicola, either by the health care professional, or indeed Nicola herself.<sup>68</sup> Each is therefore free to disclose the information, subject solely to Nicola's wishes.

Moreover, even if a duty of confidentiality were owed, protection of the interest in not knowing information cannot flow from this legal construct. It would be unreasonable to suggest that the duty can be breached by one relative telling the person to whom the duty is owed the information in question. A duty of confidence is breached when confidential information is used or disclosed to those outside the confidential relationship. A breach of duty is constituted by making the information in some way public. Precisely how public any use or disclosure must be is a matter of debate, but it cannot be the case that disclosure of information from one party to a confidential relationship to the other party in anyway makes the information public. This then means that even if a duty of confidence is owed in our scenario by Nicola to her female relatives, she could not breach that duty by disclosing the information to the women themselves. Thus confidentiality provides no means to protect the interest that these women have in not knowing information about themselves.

Indeed, one might suggest it is the confidential relationship that receives protection and not the information conveyed between the parties. If this were not true, then why would it

matter who was in possession of the information or how they came by it? If the information were protected, then it would be protected irrespective of the circumstances in which it was imparted or received. The confidential quality of the information would be enough to merit protection. In the authorities cited above, however, it is clear that the decisions have little to do with the nature of the information and everything to do with the recognition of a relationship as privileged. The right of confidentiality is, therefore, a right in personam and not in rem.

The consequence of this is that the concept of confidentiality does not accord a right to relatives of a proband to control the flow of familial genetic information toward themselves. If they are to be informed of familial information, then this either will be as an exercise of the right of the proband to control his or her own information, or as a result of a discretion exercised by a health care professional to breach confidentiality without fear of sanction.<sup>69</sup> More importantly for present purposes, it is not clear that, even if a duty of confidence is owed between relatives concerning their common genetic information, such a duty could ever be breached simply by telling relatives themselves about their own personal information. It therefore becomes apparent that the law of confidence cannot address the question of protecting a possible interest in not knowing information, such as might arise in the scenario described above.

### C. The Protection of Privacy Interests by Autonomy and Confidentiality

This section draws the first part of this article to a conclusion. We have examined the nature of the interests that individuals have in genetic information and these can be described as being of two sorts. First, there are interests that concern issues of security of existing information, and second, there are interests that relate to the protection of the self from unwarranted intrusion, including intrusion with information about one's own being. We have seen in the last two sections how the existing concepts of autonomy and confidentiality fare in protecting the latter type of interest and we can conclude that the major problem arises in the context of interest in not knowing. While both confidentiality and autonomy can, to an extent,

help to protect interests concerning access and control of known genetic information, these concepts, alone or in combination, cannot furnish a useful, precise, and effective means of articulating all of the interests involved, or of protecting them in an appropriate fashion. The solution that is proposed in the next section is that of a concept of genetic privacy, for it is submitted that the interests which are at stake are, in essence, privacy interests. Presently, therefore, a definition of privacy is argued for and defended within the context of the wider debate about the value of privacy per se and its current protection both at common law and under the United States Constitution. This novel definition is then applied to the genetic information scenario to show how the privacy interests involved can best be protected by an appeal to privacy itself.

## VI. PRIVACY

### A. Privacy: A Definition

A valuable concept of privacy should reflect the privacy needs of persons in society. In western society these needs are reflected in two views of privacy. First, privacy can be seen as a state of non access to the individual's physical body or psychological person; what I will call spatial privacy. Second, privacy can be viewed as a state in which the individual has control over personal information; what I will term informational privacy. From these two conceptions of privacy, one can deduce a single unifying definition: privacy as a state of separateness from others. Thus, privacy should be taken to refer to a state in which an individual is separate from others, either in a bodily or psychological sense, or by reference to the inaccessibility of certain intimate adjuncts to their individuality and personality, such as personal information. The reasons for this choice of definition will be more fully considered and properly justified in the next section.

## B. Why Protect Privacy?

A number of arguments can be offered to justify privacy protection. First, it has been posited by several commentators that a state of physical separateness from others is necessary in order to allow personal relationships to begin and to grow. The levels of intimacy that typify the modern personal relationship only can be achieved by ensuring and securing separateness from others. Trust, which is essential to the establishment and maintenance of all relationships, requires not only a degree of intimacy to develop but also a currency in which to deal. An important part of that currency is personal information. Individuals trade private information both as a sign of trust and on the basis of trust. The security of the information is guaranteed by the tacit undertaking that it will not be noised abroad. In this way, personal and professional relationships flourish and an important part of the fabric of society is woven more tightly. As Fried has said:

“Love and Friendship...involve the initial respect for the rights of others which morality requires of everyone. They further involve the voluntary and spontaneous relinquishment of something between friend and friend, lover and lover. The title to information about oneself conferred by privacy provides the necessary something. To be friends or lovers persons must be intimate to some degree with each other. Intimacy is the sharing of information about one's actions, beliefs, or emotions which one does not share with all, and which one has the right not to share with anyone”.<sup>70</sup>

Second, a degree of separateness - that is, being alone with no company or merely selected company - allows the individual personality to reflect on experiences and learn from them. Constant company, and so constant interaction, deprives the individual of time to assimilate life experiences and to identify with one's own individuality.<sup>71</sup>

Third, it has been argued that the modern psychological make-up of individuals is such that a degree of separateness is required to ensure that individuals retain a degree of mental stability. Jouard has put a forceful argument that (western) public life puts considerable strain on



individuals who must assume certain personae to integrate with others. These personae, not being full and true reflections of the personality of the individual, cannot be maintained indefinitely without serious psychological consequences. A state of privacy allows the masks to be dropped and a degree of release to be obtained.<sup>72</sup>

Fourth, tangible harm can come to an individual who is not granted a degree of privacy. As regards spatial privacy, invasion on the body, which is unauthorized, is disrespectful of the individual and might, of course, cause physical harm. The criminal and civil laws of assault recognize and protect to a degree the inviolability of the human body. Perhaps less obvious but no less valid, however, is the mental harm that can arise if one's spatial privacy is not respected. For example, clandestine observation can produce profound feelings of violation in individuals even although no actual physical contact occurs and/or no personal information is gathered.<sup>73</sup> Similarly, unauthorized use or disclosure of personal information can lead to harm to individuals. Information about one's personal condition, behavior or habits, which others find distasteful, can lead to individuals being ostracised from communities or becoming the object of violence and discrimination. As Greenawalt puts it:

“One reason why information control seems so important is precisely because society is as intolerant as it is, precisely because there are so many kinds of activity that are subject to overt government regulation or to the informal sanctions of loss of job or reputation”.<sup>74</sup>

There is, moreover, one final argument in support of the protection of privacy. While the above arguments concentrate on individual interests, it is important to recognize that there are also public interests in privacy protection. For example, it can be argued that it is in the public (societal) interest to have a community inhabited by complete individuals as opposed to two-dimensional characters.<sup>75</sup> For a society that holds the individual in esteem and seeks to accord him or her respect, it is surely in the public interest to reduce to a minimum all potential harm to individuals. Moreover, it should not be overlooked that harm can come to society itself if privacy is not respected. If the element of trust which is so crucial to the development of

relationships is lost, because individuals cannot seek and receive guarantees about the security of information, important and valuable information will not be communicated. This can render important social organs powerless to deal with a variety of social conditions. This is especially true in the health care context, where physician-patient trust is seen to be essential to an effective and beneficial therapeutic relationship.<sup>76</sup> If that trust is compromised because individual privacy is not protected, then public and private health may suffer as a result.

These arguments support the effort to protect privacy as a construct of general social good. The specific definition of privacy advanced in this work is, however, two-pronged: it relates both to spatial and informational privacy. There are strong reasons for recognizing and protecting both kinds of individual privacy - reasons that also are grounded in both private and public interests. These are best discussed in the context of the health care setting for which the definition of privacy that is offered is intended.

### C. Spatial and Informational Privacy: A Medical-Legal Definition of Privacy

Privacy was defined above broadly as a state of separateness from others. Such a state encompasses two forms of separateness. Physical or psychological separateness from others (spatial privacy) and separateness of certain intimate adjuncts to one's personality; namely personal information (informational privacy). The argument for viewing privacy in such terms is as follows.

First, let us consider informational privacy. Undoubtedly, patients have considerable interests in their own medical information because, *inter alia*, it can be used against them by others and this can lead to harmful outcomes such as upset, discrimination, prejudice, etc. Informational privacy therefore concerns the interest of the patient in maintaining such information in a state of non access and preventing unauthorized use or disclosure of the information to third parties. For the purposes of this article, the information in question is

genetic information. Thus, a concern about informational privacy is a concern about maintaining a state of non access to personal genetic information. For reasons already articulated, an interest in genetic informational privacy can be claimed both by a proband and his or her blood relatives.

Second, let us examine spatial privacy. It is submitted that, as a caveat to the above, a concept of privacy that is defined solely in informational terms does not adequately reflect the interests patients have in privacy matters and so cannot purport to protect comprehensively such interests. The concept of spatial privacy is therefore offered as a complement to the concept of informational privacy. The concern of spatial privacy is not simply information. Rather, spatial privacy relates to the sphere of the self - a bubble of privateness around the individual that cannot and should not be invaded without due cause. Such a sphere of separateness from others can be invaded either by unwarranted physical contact (such as unauthorized treatment or continued futile medical treatment) or by uninvited intrusion into the sphere of psychological integrity that individuals create for themselves. In the context of genetic information, it is submitted that spatial privacy can be invaded by the revelation of genetic data about an individual to that self-same individual, if there is no indication that the individual would want to know such information. This cannot appropriately be seen as an informational privacy issue because this latter privacy interest concerns the interest in maintaining non access vis-à-vis third parties. In the example under discussion, the concern is revelation of information about oneself to oneself. Informational privacy focuses on the control that an individual can exercise over his/her personal information. Spatial privacy protection cannot focus on control of information because its domain is the maintenance of a state of ignorance, wherein information is unknown and therefore beyond the reach of any meaningful exercise of control. One cannot control that which one does not know to exist.

The justifications for this two-fold conception of privacy are numerous. First, the conception of what is private in lay terms accords to a high degree with the view of privacy advocated in this work.<sup>77</sup> This is important because it goes a long way to helping us formulate a

view of the law that can address actual social needs. Moreover, this definition pinpoints interests that already are recognized by privacy laws in the United States, yet which are currently under-protected, as will be demonstrated presently.

Second, to define privacy as a state rather than a right or a claim helps us to describe the concept while at the same time avoids imputing value to it. As has been noted, privacy is defined as a state of separateness from others, be that society in general, the family, or other individuals. This is not to say that others cannot enter that sphere, nor that individuals simply can act howsoever they would wish when in such a sphere, nor that such a state necessarily protects undesirable activities. Rather, it is to say that *prima facie* a state of privacy places the individual apart from others.<sup>78</sup> Yet, merely to say that I am apart from others will not always lead us to conclude that I am in a state of privacy. For example, if I am marooned on an island, then I am certainly apart from others, but few of us would say that I have privacy. This is in part because privacy implies something more than mere isolation, which can be seen as undesirable. To be in a state of privacy, one must be in a context where there are others from whom one can be separate. On a desert island this is not possible for one is alone. This is isolation, which implies a state of enforced non access to others. Privacy, on the other hand, is a state that easily can be relaxed or maintained because it occurs in a social setting. Isolation concerns the removal of individuals from a social context and therefore cannot accurately be described as privacy.<sup>79</sup>

By corollary, simply because I am in the presence of others does not necessarily mean that I cannot claim privacy interests. For example, an aspect of spatial privacy is the interest in maintaining bodily integrity. It is not because I am in a crowd that unwarranted interferences with my bodily integrity are not offensive and cannot be classed as invasions of privacy. Intentional contact with my person by another easily can be seen as an invasion of privacy. However, incidental touchings are a necessary and obvious part of entering a crowded public forum and could not reasonably be treated as an invasion of privacy.<sup>80</sup> Similarly, one would not say that one's privacy interest in not being observed is invaded by being in a crowd. Arguably, in

such cases, one has consented to a degree of observation or physical contact - that which flows directly and naturally from one's presence in the public sphere.<sup>81</sup> This having been said, if one's movements were to be recorded clandestinely, then a strong argument could be made that this does indeed infringe privacy interests. There is a considerable difference between the anonymity of the crowd and the specific identification of an individual within a crowd. In the former case, any observation which occurs is merely incidental and readily can be anticipated by the individual in question. If, however, one is being clandestinely observed, then one cannot reasonably anticipate being the focus of someone else's attention. Moreover, one becomes a means to someone else's end: a factor which, in itself, is offensive and disrespectful of the individual.<sup>82</sup> The specificity of the information obtained by recorded observation is an additional factor that differentiates the two experiences. In like manner, the specificity of detail that can accompany genetic test results, and the implications the use of that information can have for those identified, should serve to heighten our privacy concerns.

Fourth, to describe privacy as a state and therefore to seek to offer a neutral description of the concept of privacy does not preclude us ultimately from attributing value to such a state. Nor does it prevent us from seeking to accord (legal) protection to such a state for the good ends that it can further and for the interests it can protect. It already has been argued that a state of separateness can protect good ends - both private and public. But, in essence, such a state can be seen as one in which the interests of the individual are paramount. If one chooses to accord respect and protection to such a state, then this is evidence of a degree of commitment to valuing individuals. But, the obvious question which arises from this is, why should we seek to protect such a state of privacy when we already have mechanisms for respecting individuals and protecting their interests? The response is that such existing mechanisms cannot always provide adequate protection. Furthermore, the concept of privacy advanced here allows us to recognize a broad range of interests that might otherwise go unrecognized. To view privacy either as solely concerned with personal information, or to argue that autonomy or confidentiality (or, indeed, liberty) can adequately protect privacy interests is to fail to protect important interests and to

miss many interesting nuances. This having been said, one criticism that might be levelled at the view of privacy presented here is that it confuses privacy with concepts such as autonomy, confidentiality or even liberty. For example, a state of separateness implies a state of non-interference which is arguably simply one definition of liberty or freedom. Similarly, it might be argued that the state in question is one which depends largely on the notion of autonomy - the individual as self-ruler. This would be an important criticism and even if it were not raised in respect of the definition of privacy advanced here, the relationship between privacy and these related concepts must nevertheless be examined.

#### D. Privacy and Related Concepts

Many writers associate the beginning of legal interest in privacy in the United States with the seminal article by Warren and Brandeis, *The Right to Privacy*, published in the 1890-91 volume of the *Harvard Law Review*.<sup>83</sup> From such humble beginnings was born the tort of invasion of privacy.<sup>84</sup> Warren and Brandeis examined cases drawn from areas as diverse as defamation,<sup>85</sup> breach of confidence,<sup>86</sup> and copyright,<sup>87</sup> and concluded that the common law recognised common interests in each of these actions which could be subsumed under the rubric of a general right to privacy.<sup>88</sup> This they classified as a “right to be alone”.<sup>89</sup> For present purposes, it is neither intended to praise<sup>90</sup> nor particularly criticize<sup>91</sup> this work, but rather to offer it as an illustration of a common problem which arises in the field of privacy study; namely, conflation of concepts and confusion of terminology. The association of privacy with the “right to be alone” has been made by many writers since Warren and Brandeis,<sup>92</sup> and all have been subject to the same criticism: by conceiving privacy to be a “right” to be free from intrusion or interference they have equated privacy with liberty. This is not only confusing generally, but for those who seek to argue positively about privacy it can have adverse consequences. For example, Fried has recognised that “to present privacy only as an aspect of or an aid to general liberty is to miss some of its most significant differentiating features”.<sup>93</sup> Similarly, Posner has observed: “[W]e already have perfectly good words - Liberty, Autonomy, Freedom - to describe the interest in

being allowed to do what one wants (or chooses) without interference. We should not define privacy to mean the same thing and thereby obscure its other meanings”.<sup>94</sup>

#### E. Conflation of Concepts

Today, privacy is protected in the United States at a number of different levels and by a number of different means.<sup>95</sup> Central among these are the common-law right, of which Warren and Brandeis were the progenitors and to which we shall return presently, and the Supreme Court’s creation: the Constitutional Right to Privacy. This latter has been much criticised ever since it was “interpreted out” of the Constitution by the Court in 1965<sup>96</sup> in *Griswold v Connecticut*.<sup>97</sup> Once again, however, one major criticism which is frequently voiced is the alleged confusion of ‘privacy’ with ‘liberty’. Parent, for example, argues:

“The defining idea of liberty is the absence of external restraints or coercion. A person who is behind bars or locked in a room or physically pinned to the ground is unfree to do many things. Similarly, a person who is prohibited by law from making certain choices should be described as having been denied the liberty or freedom to make them. The loss of liberty in these cases takes the form of a deprivation of autonomy. Hence we can meaningfully say that the right to liberty embraces in part the right of persons to make fundamentally important choices about their lives and therewith to exercise significant control of different aspects of their behaviour. It is clearly distinguishable from privacy, which condemns the unwarranted acquisition of undocumented personal knowledge.”<sup>98</sup>

Parent’s is of the opinion that all of the United States constitutional privacy cases “conflate the right to privacy with the right to liberty”.<sup>99</sup> While one might not agree with his particular definition of privacy, his point on confusion of concepts is, nevertheless, a valid one. Wagner DeCew offers the following explanation: “Given early association of a legal right to privacy as a right to be let alone and the well-known explanation of a concept of negative liberty in terms of freedom from interference, it is hardly surprising that privacy and liberty should often be equated”.<sup>100</sup>

There is, however, an additional problem which stems from the fact that although one may accept wholeheartedly that privacy and liberty, as defined by Parent, are completely separate, it does not necessarily follow that the two concepts raise issues wholly unconnected with each other. Furthermore, as DeCew points out in relation to the case law, “it is not at all clear that Parent has shown that the constitutional privacy cases involve no ‘genuine’ privacy interests”.<sup>101</sup>

Clearly, however, the two concepts are by no means synonymous. As DeCew herself states, it is simple to show how one's notion of privacy can be shown to be distinct from that of liberty. The example she gives is where one's privacy is being constantly invaded by surreptitious surveillance, of which one is unaware, thereby having no effect on one's liberty. To this one could add the example of genetic testing where information is gathered about oneself from family members when one is wholly ignorant of the fact. Both of these examples involve invasion of one's private sphere yet entail no impingement on one's liberty. DeCew comments: “While the word ‘privacy’ could be used to mean freedom to live one's life without governmental interference, the Supreme Court cannot so use it since such a right is at stake in every case. Our lives are continuously limited, often seriously, by governmental regulation”.<sup>102</sup>

In fact, the Supreme Court has expressly rejected this idea.<sup>103</sup> However, we can once again accept that while this particular conflation of privacy with liberty might be wrong, this does not necessitate that we reject completely the possibility of a relationship between the two concepts. Just as Wagner DeCew gives examples of privacy issues that do not involve liberty, and vice versa, she equally talks of autonomy examples which exclude all mention of privacy.<sup>104</sup> She qualifies this immediately, however, by acknowledging that,

“a subset of autonomy cases, however, certain personal decisions regarding one's basic lifestyle, can plausibly be said to involve privacy interests as well. They should be viewed as liberty cases in virtue of their concern over decision-making power, whereas privacy is at stake due to the nature of the decision. More needs to be said about which decisions and activities are private ones, but it is no criticism or conflation of concepts to say that an act can be both a theft and a trespass.



Similarly, acknowledging that in some cases there is both an invasion of privacy and a violation of liberty need not confuse those concepts".<sup>105</sup>

What a defense of privacy can do, however, is protect some forms of liberty - principally those relating to the personal sphere of individuals' lives. The same is true for autonomy, and, in the case of personal information, this can be said of confidentiality too. Many commentators who concern themselves with the concepts of liberty or autonomy face problems of conceptual confusion, difficulty of definition, and ambiguities of scope. Beauchamp and Childress, for example, point out that autonomy is terribly conceptually confused and "not a univocal concept in either ordinary English or contemporary philosophy"<sup>106</sup>. Dworkin similarly considers a plethora of definitions of autonomy offered by writers in that field almost none of which is in conformity with any another.<sup>107</sup> And Berlin has noted in the context of liberty that: "Almost every moralist in human history has praised freedom. Like happiness and goodness, like nature and reality, the meaning of this term is so porous that there is little interpretation that it seems able to resist".<sup>108</sup>

As a way through this conceptual mire it is helpful to recognize that notions such as liberty, autonomy and privacy are interrelated. Indeed, one could go as far as to say that they are interdependent, each one relying on the other to fulfil its true function in the best possible way.<sup>109</sup> Consider the impossibility of making autonomous choices without a degree of freedom from interference.<sup>110</sup> Consider the residual value of liberty if one's life choices are never respected. And, consider whether it is feasible to be truly free or fully autonomous without some sphere of the private? Liberty and autonomy cannot properly fulfil their function or potential in protecting individuals and their interests without a concomitant commitment to a respect for privacy. Each of these concepts performs the same function, albeit in different ways: each represents an expression of the fundamental respect which a liberal society has for its citizens. Yet, each is also open to criticism as ill-defined, anticomunitarian and conceptually obfuscated. Accordingly, these reasons are insufficient in themselves to deny a healthy respect for privacy.

This having been said, it might be that we see liberty and autonomy as ends in themselves rather than as means to an end, while we may view privacy purely as a device to achieve a certain end. Even so, it is submitted that it is not necessary to show privacy to be a fundamental and ultimate value of itself in order to argue validly for its protection. Furthermore, as Gavison points out:

“Privacy has as much coherence and attractiveness as other values to which we have made a clear commitment, such as liberty. Arguments for liberty, when examined carefully, are vulnerable to objections similar to the arguments. . .[against] privacy, yet this vulnerability has never been considered a reason not to acknowledge the importance of liberty, or not to express this importance by an explicit commitment so that any loss will be more likely to be noticed and taken into consideration”.<sup>111</sup>

Gavison argues that the case for an explicit commitment to privacy is made by pointing out the distinctive functions of privacy in our lives. Are there, then, specific functions for privacy to perform over and above a general support for other concepts such as liberty and autonomy? It has been argued thus far in this article that this is indeed the case in the context of genetic information. We have seen how concepts such as autonomy and confidentiality do not, and cannot, address the concerns and interests that surround the availability of genetic information. Moreover, it is submitted that, while the Constitutional right to privacy and the common law tort of invasion of privacy reflect the interests that are protected by the view of privacy described above, these conceptions of privacy are currently inadequate in their protection of such interests. Thus, for example, it might be argued that the interest protected by the Constitutional right corresponds to a spatial privacy right, in that it affords individuals a zone of personal space into which the state cannot intrude without adequate justification. The development of this right has been hampered, however, by the piecemeal nature of court jurisprudence, and by the inconsistencies of the Supreme Court itself in recognizing the parameters of the interest it believes it is protecting.<sup>112</sup> Moreover, the right in question is good only against the state, and would not provide any horizontal protection vis-a-vis other individuals. Most importantly, towards the end of the 20<sup>th</sup> Century, the Supreme Court signalled a rejection of privacy as the key

value under which Constitutional rights of individuals in the health care context are to be protected, preferring instead liberty under the Fourteenth Amendment.<sup>113</sup> For these reasons, the notion of a Constitutional right of privacy is an inappropriate means to protect the spatial privacy interests in genetic information. Nonetheless, the history of jurisprudence of such a right demonstrates well the recognition of the need for adequate protection of interests of this sort.

Relatedly, one might speculate on the common law right of privacy as a means of protecting informational and spatial privacy. As a right in rem, this privacy right is good against the world at large, and so is unlike the right of confidentiality, which must be owed specifically and voluntarily to one individual or group of individuals.<sup>114</sup> We can test the efficacy of this privacy right by applying it, once again, to our imaginary scenario. The relatives might, for example, claim that an invasion of their privacy had occurred if certain uses of the information were employed, either by the health care professional, or arguably, Nicola herself. But can this vision of privacy protect the interest in not knowing? Of the four subsets of the privacy tort that have been identified,<sup>115</sup> the most appropriate might be public disclosure of private facts or unreasonable intrusion upon the seclusion of another. The first of these, however, would only assist if the information were revealed, as with confidentiality, to third parties outside the familial relationship, and no interest would be infringed if the women themselves were told the news. With respect to unreasonable intrusion, it might be thought that the offensive intrusion could be the receipt of burdensome information, but a perusal of the case law does not bear this out as a means of constituting the tort. Rather, an element of intentional invasion of private space is required, which is bound up with the possibility that personal information will be acquired or removed from that space by unacceptable means, rather than, as with our concern, that personal information will be added to that personal space.<sup>116</sup> Thus, the tort is constituted when an illegal search of one's property is carried out,<sup>117</sup> or when one's home is physically invaded,<sup>118</sup> or when eavesdropping or spying occurs,<sup>119</sup> or even when one is the subject of harassing telephone calls.<sup>120</sup> There is no authority to suggest that an actionable tort is committed by adding private information to the private sphere. It would seem that the conceptual underpinnings of the tort

do not encompass such an invasion. Thus, the common law right of privacy cannot help to establish a valid legal basis for a right not to know information. The focus of the tort on the need to extract information from the private sphere (usually with a view to placing it in the public sphere<sup>121</sup>) renders it ill-equipped to protect against such intrusions into the private sphere as occur when an interest in not knowing is compromised. The parallel that might be drawn then, is that the common law tort is more akin to an informational privacy right, and not a spatial privacy right.

These conclusions about current privacy protection in the United States should not lead us to the belief, however, that pursuing further privacy protection is a fruitless task. Rather, as has been argued above, there can be considerable value in recognizing the importance of protecting privacy. The definition of privacy proposed in this article finds its roots in moral notions about individuality, and presupposes social norms, such as respect for individuals. In this it is allied with the related concepts of autonomy, confidentiality and liberty, for all of these concepts perform essentially the same function - to define how individuals are perceived and treated in western society and to establish and maintain the boundaries between the individual and society. Moreover, these concepts are necessary adjuncts to a view of human dignity and respect that is prevalent in our society. To see privacy in such terms allows one to comprehend better why a state of separateness should be sought. It further allows us to put forward valid and legitimate reasons for arguing that such a state should be protected and that invasion should only be on legitimate grounds and for legitimate reasons. Below, a more specific defense of privacy is presented, which applies the definition here advanced to the genetic information scenario outlined above to show that privacy in se can best protect the interests involved.

## VII. A RIGHT NOT TO KNOW: A PRIVACY PERSPECTIVE

A spatial privacy analysis underscores a right not to know information. If, in the context of a dilemma about whether someone should be told, the individual has no knowledge at all that

familial information exists, then the spatial privacy interest stands as a *prima facie* bar to the person being approached and told the information. Spatial privacy requires that, before such an approach is made, we consider how the individual might be harmed by disclosure and what good, if any, might come from disclosure. It requires that we reflect on the act of disclosure and places the onus on us not to disclose unless faced with compelling reasons to do so. Finally, it goes some way to ensuring that the decision-maker does “not rest content with assumptions that flow from preconceived value preferences”.<sup>122</sup> That is, a privacy analysis reveals the broader and more complex reality of scenarios involving genetic information. This does not happen when we analyze the problem from the perspectives of autonomy or confidentiality. As we have seen, autonomy is susceptible to argument for autonomy enhancement through disclosure of information. On the other hand, confidentiality permits wide exceptions – such as the amorphous public interest - whereby disclosure can easily be justified at the discretion of those in possession of confidential information and when the value judgements of those persons dictate when information is so disclosed.<sup>123</sup>

Thus, in the circumstances of our scenario, Nicola must consider the privacy interests of her female relatives in not knowing the familial genetic information. It has been argued from the perspective of autonomy that Nicola could approach her relatives with the news of her own condition and let them decide for themselves whether they should do something about discovering their own genetic composition. From the perspective of privacy, however, Nicola must seriously consider the spatial privacy interests of her relatives. This might lead her to conclude that the information should not be imparted, for example, in the case of the sister who is unlikely to take advantage of the cure available because she is phobic about operations, or the cousin who is likely to react badly to the information given that she is prone to bouts of depression.

Our spatial privacy analysis provides Nicola with a more sophisticated model than is currently available from either of the concepts of autonomy or confidentiality with which to

determine how she should proceed with the news about her condition. It is undeniable that this is a paternalistic stance. It cannot be otherwise in the absence of more information about what the relatives would want. Yet, such a paternalistic approach must be accepted for what it is and not be eschewed automatically in favor of an autonomy-enhancing disclosure. While autonomy-based arguments tend to create an imperative to let the individual make the personal choice, too frequently this amounts to an abrogation of responsibility on the part of the discloser of the information; for, with the passing of the information goes too the responsibility for assisting in how the information should be used. But, the transference of the burden of decision does not in itself absolve the first party of his or her moral obligations to the recipient of the information. And, because of the susceptibility of autonomy to value-laden enhancement or facilitation arguments, it is often overlooked that decisions to enhance the autonomy of another are just as paternalistic as decisions not to disclose information at all.

What should happen in the case of a refusal based on limited knowledge? For example, if Nicola's cousin, Norma, was known to have expressed a disinclination to know her own health status when she was aware of the family history of disease, should she nevertheless be told? In these circumstances we have an indication that an individual might not wish to know information. Autonomy indicates that we should respect such a wish and a spatial privacy analysis gives us another good reason to do so. It is accepted that a privacy analysis does not necessarily make it easier for us to respect a wish not to know if that wish seems irrational (for example, if a cure for the condition is available and yet refusal is still made) but, it does give us all the more cause to reflect that the refusal should be respected nonetheless. In addition, while autonomy-based arguments can be undermined because the subject in our scenario is not in full possession of all material facts to enable her to make a truly autonomous decision, a privacy paradigm offers a *prima facie* starting point of noninterference, which places the onus of justifying disclosure firmly on the shoulders of those who would do so.

None of the above should be taken as suggesting that disclosure should never be made. Rather, it is offered as a model for reevaluating the information disclosure decision-making process, and for considering the weight and merit of a range of factors in deciding if, when, and in what circumstances, a disclosure should be made. Furthermore, it should not be forgotten that hypotheticals rarely translate easily into real-life situations. It is acknowledged that, in a family context, it is very difficult to keep matters secret or private. Also, faced with the prospect of death, many would consider that everyone would wish to know of a predisposition to disease, no matter how upsetting the knowledge. This article cannot adequately address such issues. But, the point to be made is that the privacy analysis advanced here can be seen as a reflection of a wider trend in medicine and the care of others. The principle of sanctity of life is no longer seen to be the governing value in health care. Quality of life has taken over that role. And, acceptance of this requires many paradigm shifts. If it were thought that the supreme value were to save life at all cost, then subtle privacy issues such as those advanced here would not arise. If, however, one values quality of life and accepts that we might prefer quality to the mere continuation of life, then this requires us to acknowledge that individuals might have an interest in preserving their current quality of life, even if that comes at the cost of life itself. The privacy model suggested here provides us with one way of seeking to respect such an interest.

Further utility for this model can be found when claims to have access to familial genetic information come from outside the family context. The requests of employers or insurers that individuals undergo genetic testing can be seen as an invasion of privacy given that these individuals are required to know information about themselves that they might not otherwise discover or seek out. In the balance of interests that could be undertaken, it would be hard to justify the promotion of the interests of employers and insurers – being primarily financial – over the significant personal spatial privacy interests of individuals that might be compromised by such requests. While the focus of this article is the family unit, this brief example demonstrates the potential extension of our privacy model to other areas. It is a sphere that require considerably closer examination.

## VIII. WHAT KIND OF GENETIC PRIVACY RIGHT SHOULD THERE BE?

If the above arguments are accepted, and the current legal protection of privacy rejected as inadequate, then the question that arises is, what kind of privacy right should there be? We can approach this question from several different perspectives. On the one hand, we can consider other means within the existing law for recognising these privacy interests. This could be in one of two ways: (1) by the refusal to impose any duty to disclose through the law of negligence, (2) by recognizing or creating a common law duty not to disclose. Alternatively, we could contemplate the introduction of a new statutory right of privacy specifically designed to protect the privacy interests in question.

### A. No Duty to Inform

The negligence action has been used widely in tort law to delimit the extent of the duty of care that a physician owes to patients. Occasionally, however, a duty is deemed to be owed to persons outside the therapeutic relationship,<sup>124</sup> and, in such circumstances, the courts rely heavily on policy arguments to shape and temper such extensions of the law. The beginnings of a trend to extend the duty of care to relatives of persons diagnosed with genetic disease can be discerned in a number of states. Thus in Pate v. Threlkel,<sup>125</sup> the Florida Supreme Court specifically addressed the question: “Does a physician owe a duty of care to the children of a patient to warn the patient of the genetically transferable nature of the condition for which the physician is treating the patient?” In answering this question in the affirmative, the court concluded that:

“...when the prevailing standard of care creates a duty that is obviously for the benefit of certain identified third parties and the physician knows of the existence of those third parties, then the physician’s duty runs to those third parties...a patient’s children fall within the zone of foreseeable risk.”<sup>126</sup>



It was at pains to stress, however, that the duty did not require that relatives be approached directly by the physician: “the duty will be satisfied by warning the patient”.<sup>127</sup>

This view is unsatisfactory as a matter of policy for two reasons. First, it says nothing about the nature of the physician’s duty if the patient refuses to disclose to relatives. Second, it assumes that the interests of patient and relatives necessarily coincide. For example, one can foresee circumstances in which it might not be in a patient’s interests to be told that he or she is dying of a genetic condition, yet a failure to do so would be a breach of the physician’s duty to the patient’s relatives. The two duties of care are not, therefore, always reconcilable.

A 1996 decision of the Superior Court of New Jersey has addressed at least the first of these problems. In Safer v. Estate of Pack,<sup>128</sup> the court refused to follow the Florida court’s restriction of the duty, and “declin[ed] to hold...that, in all circumstances, the duty to warn will be satisfied by informing the patient”.<sup>129</sup> The court continued: “It may be necessary, at some stage, to resolve a conflict between the physician’s broader duty to warn and his fidelity to an expressed preference of the patient that nothing be said to family members about the details of the disease”.<sup>130</sup> Here, the court contemplates preferring a physician’s duty of care to third parties to the patient’s right to confidentiality. That it does so at least recognises that the physician’s duty of care to those third parties is separate from the relationship the physician has with the patient (albeit that it might have its origins in that relationship). Furthermore, it recognizes that the requisite standard of care should come from the physician and should not be discharged merely by telling the patient about his or her condition.

But, even if this line of authority is thought to be persuasive,<sup>131</sup> the fundamental premise for extensions of this sort in tort law should not be forgotten; namely, that public policy considerations must dictate the future course of the negligence action. It is for the courts to decide this matter, and a number of factors have a direct bearing on whether such an extension should be made. Several considerations should be immediately apparent, such as the burden that

a duty would place on health care professionals,<sup>132</sup> the difficulty in knowing who should be contacted and how,<sup>133</sup> and the possible detrimental effect that such a duty would have on the physician-patient relationship if confidentiality can be disregarded in favor of the duty to disclose.<sup>134</sup> But, of most importance in the present context, the courts should not rely unquestioningly on an assumption that nondisclosure is necessarily a (legal) harm.

As has been argued above, the interest in not knowing can be very important, and it will not be served by imposing a duty on health care professionals to make disclosures without first considering the consequences, both for the patient and the patient's relatives to whom disclosure will be made. One way, therefore, to recognize and protect the interest in not knowing would be refuse to endorse the extension of tort law to impose a duty to disclose. The problem with such an approach is that it leaves the matter of the recognition of spatial privacy interests to the judiciary, which can only recognize such interests as and when relevant disputes come to court. Also, and more importantly from the individual's perspective, such an approach does not accord any right of compensation to those who have had their privacy interests invaded. It merely acts to pay abstract lipservice to the interests in question.

#### B. A Duty Not to Inform

An alternative means to enshrine a right not to know in law would be to make an unauthorized disclosure a cause of action leading to the payment of damages, either for consequential harm or, simply, because the privacy of the individual had not been respected. As far as the common law is concerned, however, the analysis carried out above has shown that the primary concern of the privacy tort is with informational privacy interests and not spatial privacy interests. It is, thus, ill-equipped to be developed along such lines, absent some act of unprecedented judicial activism. Thus, in the absence of a viable alternative at common law,<sup>135</sup> any right to compensation would henceforth require to be introduced by statute at the state or federal level.

During the 105<sup>th</sup> Session of Congress, 110 bills seeking to protect genetic privacy were introduced. None was debated beyond the sub-committee stage.<sup>136</sup> And, while a number of states have taken the initiative to introduce protective measures,<sup>137</sup> no federal initiative has ever been successful. Yet, as Starr has pointed out: “Almost everyone agrees that the absence of stronger protections for the privacy of health data is a national problem and that this problem has become more urgent in recent decades”.<sup>138</sup> The Health Insurance Portability and Accountability Act of 1996 set a deadline of August 21, 1999 for Congress to enact federal health privacy legislation, but this deadline passed without action. In default, the Act empowers the Secretary of the Department of Health and Human Services to introduce privacy regulations. A proposed rule on privacy was instituted on 3 November 1999, and the period for public comment closed on 17 February 2000. At the time of writing, no regulations have been instituted. In this period of inaction and uncertainty, it is therefore apposite to look for inspiration to model federal legislation designed specifically to address genetic privacy concerns.<sup>139</sup>

### C. The Genetic Privacy Act

The Genetic Privacy Act (GPA) was produced for the Human Genome Project's Ethical, Legal and Social Issues division by George Annas, Leonard Glantz and Patricia Roche of Boston University's School of Public Health.<sup>140</sup> This draft model law is in the format of a federal statute and has already been a source of inspiration for several state legislatures<sup>141</sup>.

The introduction to the Act states:

[T]he overarching premise of the Act is that no stranger should have or control identifiable DNA samples or genetic information about an individual unless that individual specifically authorizes the collection of DNA samples for the purpose of genetic analysis, authorizes the creation of that private information, and has access to and control over the dissemination of that information.

Thus, the GPA envisages a highly individualistic approach to the question of control of genetic samples and information. It should be noted, however, that the GPA defines the term "private genetic information" to mean

any information about an identifiable individual that is derived from the presence, absence, alteration, or mutation of a gene or genes, or the presence or absence of a specific DNA marker or markers, and which has been obtained; (1) from an analysis of the individual's DNA; or, (2) from an analysis of the DNA of a person to whom the individual is related<sup>142</sup>.

This clearly seeks to take account of the interests that relatives of a "sample source" can have in genetic information. And yet, the GPA gives a property right in the DNA sample to the sample source.<sup>143</sup> Moreover, it is not clear how well the distinction is drawn between a DNA sample and private genetic information derived from a sample.<sup>144</sup> Axiomatically, the first is unique and personal to the person from whom the sample was taken. The same is not true of the information, but the GPA nevertheless provides that the exclusive right over such information (as with samples) is retained by the sample source.<sup>145</sup> The provisions of §101(b)(8) stipulate, however, that, prior to the collection of a DNA sample from individuals they should be informed, among other things that "the genetic analysis may result in information about the sample source's genetic relatives which may not be known to such relatives but could be important, and if so the sample source will have to decide whether or not to share that information with relatives".<sup>146</sup>

It is fortunate that the text of the GPA is accompanied by a commentary prepared by its authors in which they seek to clarify their general aims and to expand upon the specific terms contained therein. Of the above provision, they say the following:

"Creating either a contractual or statutory obligation for individuals to share [genetic] information with their family members would not only be unprecedented, but inadvisable. The creation of new substantive rights or duties of family members is not our intention and is beyond the scope of this Act. However, because the Act creates rules that govern the

use and disclosure of information, it is imperative that individuals be informed of the fact that by seeking genetic information about themselves through genetic analysis, they may also become privy to information about other family members who would also want and/or need such information...[w]hile it will be an individual choice as to whether or not to share that information with others, this disclosure should instigate discussion between the sample source and the collector of the sample".<sup>147</sup>

Thus the GPA allows sample sources to decide for themselves whether to disclose genetic information to relatives. Many would argue that this is not necessarily a bad thing because often such a person will be better (or even best) placed to establish how relatives might feel about receiving such information. However, the GAP does not give any guidance to a sample source on how to decide whether or not disclosure should be made. In particular, there is no recognition of the possible spatial privacy interests which relatives who are the potential recipients of such information might have in not knowing. If it is accepted that individuals can have valid interests in such notions, then it is submitted that an Act that purports to deal with genetic privacy should include provisions aimed at recognizing and protecting such interests.

The only part of the GPA to recognize such interests is that concerned with minors. Section 141 of the Act provides as follows:

(a) INDIVIDUALS UNDER 16 -- ...the individually identifiable DNA sample of a sample source who is under 16 years of age shall not be collected or analyzed to determine the existence of a gene that does not in reasonable medical judgment produce signs or symptoms of disease before the age of 16, unless :

(1) there is an effective intervention that will prevent or delay the onset or ameliorate the severity of the disease; and

(2) the intervention must be initiated before the age of 16 to be effective; and

(3) the sample source's representative has received the disclosures required by section 101 of this Act and has executed a written authorization which meets the requirements of section 103 of this Act and which also limits the uses of such analysis to those permitted by this section.

The authors justify these provisions as follows:

There are two reasons for this prohibition on the exercise of parental discretion. First, if someone learns that the child is a carrier of a gene that disposes the child to some condition later in life, this finding may subject the child to discrimination and stigmatization by both the parents and others who may learn of this fact. Second, a child's genetic status is the child's private genetic information and should not be determined or disclosed unless there is some compelling reason to do so.<sup>148</sup>

This corresponds to arguments that have been made above concerning the spatial privacy interests of individuals. Arguably, the GPA here recognizes the spatial privacy interests of children, and further, it recognizes that these should not be invaded without due cause.<sup>149</sup> The GPA is remiss, however, in not recognizing the spatial privacy interests of all persons about whom genetic information is known but who have not sought it out themselves.

Of course, the situation of the minor is not in all respects the same as that of the adult relative of a proband. One clear point of difference concerns the initial generation of information. In the case of the minor, the legal prohibition concerns the initial collection or analysis of genetic material. In the case of an adult relative of a proband, this is not the point at issue because no one can (or should) prevent others from having their genetic material analysed. This is, however, a distinction without a difference for present purposes. For, the essential issue in both cases is the same; namely, the unwarranted intrusion of personal genetic information into the private sphere of the individual in question. Thus, the interest of the adult relative is not in seeking to control the proband's access to the information, but rather it is in having his or her own spatial privacy interests of non intrusion respected. For the minor, precisely the same interest is at stake. The means to protect the child's interest may lie in securing control over the minor's own sample, but simply because the same means are not available to relatives of a proband should not lead to the conclusion that the spatial privacy interests of the proband's relatives are any less deserving of protection.

Relatedly, because the minor is the proband in such cases, the minor has the primary right to decide what happens to his or her genetic sample and to any genetic information derived

from that sample. Given this, one might argue that the above provisions simply ensure that the choice of accessing genetic information be left until the child is capable of making independent choices. And so, one might conclude that no specific provision is necessary in the case of an adult because it is axiomatic that the adult may choose to know or not to know his or her own information. However, the question here is not simply one of access, but also one of non access. The interest is not merely one of control but of maintaining a state of ignorance: a state of non access to the person. Yet, the focus of the GPA on control of samples (and so on autonomy and choice) means that the child is only protected from attempts to gain specific access to personal genetic information. The minor is not protected from unwarranted disclosure of genetic information from relatives. Adults are in an equally vulnerable position. In fact, one can draw a clear parallel between the child and the unknowing adult in that, in many senses, they are both incapax with respect to the genetic information. While the child is generally incapax, the adult can certainly make a choice to know, in that the adult has the capacity to choose to know. But, to offer the individual the opportunity to choose might be to offend the very interests with which one is concerned. Thus, it is submitted that it is acceptable in the case of genetic information to adopt the position that both adult and child are incapax. The consequence of this is equally the same, namely, that neither should be approached with unsolicited disclosures of genetic information without due cause and justification.

The conclusion to be drawn is that it would not be inappropriate to extend the form of protection offered by the GPA to relatives of a proband. The prohibition on disclosure could not only cover requests for direct testing, but also could extend to unwarranted approaches to family members with genetic information about which they are unaware. The determination of a warrantable approach would need to be settled by more debate on the legitimate nature of competing interests and a proper assessment of genetic risks and consequences within the family and the wider community setting. In this way a spatial privacy right could be established which would require proper justification before a legally acceptable approach to a person could be made.

#### D. Privacy Problems

A well-defined spatial privacy right could embody a clear account of the kind of factors that would make disclosure in different circumstances acceptable or unacceptable. These factors have been described above as: (1) the availability of a cure or therapy; (2) the severity of the condition and likelihood of onset; (3) the nature of the genetic disease; (4) the nature of the genetic testing; (5) the nature of the request; (6) the question of how the individual might be affected if subjected to unwarranted information, and whether the individual has expressed any views on receiving information of this kind.

An obvious problem with this approach, however, is that the existence of a right not to know implies that a duty not to disclose information should exist in certain cases. Yet, an important factor in determining whether such a duty exists is the question of how the individual to whom the information is to be disclosed might react. This is a very subjective matter that can be especially difficult for any third party to assess. It leads to the possibility that individual A might determine that individual B should not be informed of information, when in fact individual B actually would want to know, had she or he been given the opportunity. As we have seen, the privacy argument in favor of non disclosure is based primarily on a desire to respect and not to harm the individual, but in such a case the very fact of non disclosure might cause harm and might be an act of disrespect in itself. In recognition of this, a number of additional factors could be brought to bear on the problem.

First, an objective assessment of circumstances could serve to delimit the parameters of any duty not to disclose. That is, the person in possession of the information would assess factors such as likelihood of onset and availability of cure, together with an objective consideration of what a person in the subject's position would or would not want to know. Such a reasonable subject could assume the particular characteristics of the actual subject. At the end of the day, provided that the assessment was a reasonable one, one could conclude that no legal



redress should lie against someone who had decided (not) to disclose information. The relevance of any views of the subject clearly would be significant in the assessment of reasonableness, as would the extent of the effort made by the duty-holder to seek out evidence of those views.

None of this detracts from the fact that the assessment of the factors to be considered is in itself a difficult exercise. On the one hand, the clinical data concerning the extent of risk or the likely success of therapy or cure are best assessed by health care professionals, while the question of which characteristics should be taken into account to determine if this subject should be told, is better determined by those close to the person, such as the subject's relatives. And, while a health care professional might be in a position to gather a range of data to assist in the assessment of the situation, it is far less clear whether family members are in a position to make meaningful assessments of such factors, let alone whether they should be the subject of a legal action if they disclose information in unjustified circumstances.

It is therefore submitted that it is more permissible to impose a duty not to disclose or seek information on parties outside the family milieu, or at least to require that they do so only in the most justified of circumstances. Primarily, this would affect employers, insurers, and the state. Thus, for example, requests for genetic testing by such parties would be seen to be a clear invasion of spatial privacy. This does not mean, however, that the range of interests under consideration, or their importance, should not be discussed with individuals who seek genetic testing and who might contemplate disclosure to their relatives. It is simply to admit that the law does not always have a role to play in determining what should be done with genetic information, especially within the family setting. Nonetheless, it could become a duty for health care professionals to discuss such interests with probands. The GPA requires, for example, that a number of matters be discussed with a sample source.<sup>150</sup> To this list could be added a specific requirement in respect of the interest of relatives in not knowing.

An additional defining factor for a duty not to disclose could be the need to show the reasonable prospect that a tangible benefit would come to the person to whom disclosure would be made. The benefit should be more than the facilitation of preparedness or the promotion of autonomy, and should represent some clinical benefit to the subject. Thus, for example, employers and insurers would not be able to rely on the argument that individuals can choose whether or not to undergo testing at their behest, but rather would have to show some real medical benefit to those persons to justify their requests for testing and/or access to genetic data. Also, state screening initiatives would be justified only if such a benefit could be shown.<sup>151</sup> Health care professionals similarly could be obliged to discuss with probands the likely real benefits of disclosure to relatives.

Third, even if all of the above is accepted, a concern may remain: is this approach not simply a paternalistic assessment of spatial privacy interests? To an extent it is, but perhaps this can never be avoided in circumstances where one cannot approach an individual directly to determine how to proceed. Rather, it is submitted that the worth of this approach is found in its responsiveness to broader, less atomistic interests. It is an approach that does not view the beginning and the end of ethical discourse as lying with the autonomy of individuals, but rather responds to the wide range of interests from the perspective of an ethic of care, wherein autonomy has a significant role to play, but where privacy is also required to complete the model.

Finally, as Powers has rightly pointed out, “. . . a commitment to privacy rights does not entail a commitment to absolute rights”.<sup>152</sup> Indeed, in the context of genetic privacy there are many reasons why this cannot be so, not least of which is the fact that we are dealing with a plethora of privacy (and other) interests stemming from the familial nature of the information in question. What, then, might the limits and exceptions to privacy protection be? Some of these already have been discussed above. In addition, it is difficult to reject the argument that public interest is a valid exception to such a right, just as it is a determining factor in the law of confidentiality. The classic paradigmatic tension is that between the public interest in protecting

private interests (such as privacy and confidentiality) and the protection and promotion of other public interests (such as protection of the community from harm, or freedom of the press). However, the devil is in the detail of determining what is meant by public interest in each case.

A number of well-accepted public interests are self-evident and certainly would be included in any genetic privacy legislation. These include the prevention and detection of crime, scientifically valid and ethically justified research and court ordered disclosures.<sup>153</sup> Public health initiatives aimed at particular populations similarly might be justified where, for example, tangible harm can be avoided by effective screening and treatment. Screening of newborns for phenylketonuria and hypothyroidism is acceptable on such grounds.<sup>154</sup> In each of these examples, the public in question is the community at large. But does this definition of public necessarily exhaust the concept? More specifically, when we ask who is the public in the genetic privacy public interest exception?, should this include the family of persons who have been tested for genetic conditions?

A public is a collective defined, like society, by reference to the individual. Relatively speaking, the individuals in a family unit might constitute a public by virtue of the fact that, as a common collective with a common interest in familial information, they have claim to the information in question. However, this is not to suggest that a familial public necessarily has the same common interest in the information,<sup>155</sup> for as we have seen, a number of potentially competing interests may be in play. Nor is it to suggest that a familial public, by virtue of its strength of numbers alone, should have an automatic or strong(er) claim to the information in question, as compared to the person who is the original source of the information. The balance, were there to be one, would need to be between the familial public interest weighed against another public interest, such as the interest in respecting individual privacy generally, or the public interest in protecting individuals from potentially harmful uses of their personal information.

This view of a collective familial claim presupposes, of course, that a familial public interest could be formulated. No comment is offered here on this point. While such a communitarian approach to privacy and genetic information scarcely has been contemplated,<sup>156</sup> it is a self-evident and natural corollary to the recognition of the range of claims surrounding this sort of information. If the family is to come to be seen as community in microcosm, then the collective claims and interests of that community also must be determined and weighed in any balance of values when assessing the appropriateness of any dealings with familial genetic information.

This article has sought to argue for recognition of one small area of this new field; namely, the interest not to know. But, if this thesis is accepted, and a paradigm shift is undertaken, which refocuses attention away from purely mono-individualistic, autonomy-based concerns, then the relevance of other similar claims also falls to be considered. While it has not been appropriate to do so in this article, the interconnectedness of the disparate elements of this discourse must ultimately be fully explored to determine the optimal role for the law within such a dynamic. At no point, however, should we dismiss the notion that the role of the law might, in fact, be limited in a complex domain such as this.

## CONCLUSION

The need to address privacy issues in the field of genetics has been appreciated by a number of international bodies in a number of international documents. For example, the Bilbao Declaration highlights the main problem areas likely to arise from the work of the Human Genome Project and pinpoints matters considered to be worthy of immediate attention by the legal systems of the world. Included in this Declaration is “[p]rotection of the personal privacy or confidentiality of genetic information, and determination of cases in which it could feasibly be altered or overstepped”.<sup>157</sup> Moreover, the interest in not knowing has been recognized. For example, the Council of Europe in its Convention for the Protection of Human Rights and

Dignity of the Human Being with Regard to the Application of Biology and Medicine, states in Article 10(2): “Everyone is entitled to know any information collected about his or her health. However, the wishes of individuals not to be so informed shall be observed”.<sup>158</sup> Similarly, the UNESCO Universal Declaration on the Human Genome and Human Rights states in Article 5c “[that t]he right of every individual to decide whether or not to be informed of the results of genetic examination and the resulting consequences should be respected”.<sup>159</sup> These instruments embody the best and the worst features of the dilemma that we currently face. They recognize the value of an interest which has hitherto received short shrift, but they offer mere aspirational means to protect this interest, which is without substance in the absence of specific national interventions. Furthermore, while these instruments recognize the value of rights-based discourse, they subsume the protection of the interest in not knowing within a rubric of rights of autonomy and choice, when these constructs are ill-suited to the task at hand. Thus, while these documents offer a new way of looking at genetic information, they represent only one means of addressing the problem - one that is typical of the current focus on autonomy-based argument.

This article has argued for an original concept of privacy that would provide recognition and protection of the interest that individuals might have in not knowing genetic information about themselves. Furthermore, it has offered a view as to how such an interest could be protected by legal means within a domestic system. The argument has been as much about identifying the problem and the most appropriate tools to use to solve the problem, as it has been about offering concrete means to address all of the nuanced issues that arise. It is as much an appeal to view the problem from an alternative perspective, as it is an offer of a solution to the dilemmas at hand. And, just as the solution offered is not without its problems, so the reader is invited to reflect that the current approach yields little by way of solution.

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\* Lecturer in Law, Faculty of Law, University of Edinburgh, Scotland. The ideas contained in this paper form the basis of a monograph entitled *Legal and Ethical Aspects of Genetic Privacy* to be published by Cambridge University Press in 2001. Address correspondence to Dr. Graeme T. Laurie, Faculty of Law, Old College, South Bridge, Edinburgh, EH8 9YL, Scotland. E-mail: Graeme.Laurie@ed.ac.uk

1 The Genetic Privacy Act, which is discussed in Section VIII.C below, draws a distinction  
between genetic samples and genetic information derived from samples. The Act further  
creates a property right for a sample source in his/her own sample. The Genetic Privacy  
Act and Commentary (unpublished, D.O.E. No. DE-FG02-93ER61626, Feb.28 1995).  
Text available at  
<http://www.bumc.bu.edu/Departments/PageMain.asp?Page=789&DepartmentID=95>  
2 See, e.g., Martin Richards, Families, Kinship and Genetics, in THE TROUBLED  
HELIX: SOCIAL AND PSYCHOLOGICAL IMPLICATIONS OF THE NEW  
HUMAN GENETICS 249-73 (Martin Richards & Theresa Marteau eds. 1996).  
3 Examples are ischaemic heart disease and certain forms of diabetes.  
4 See Ruth Hubbard & Richard Lewontin, Pitfalls of Genetic Testing, 334 New Eng. J.  
Med. 1192 (1996).  
5 For example, current tests for cystic fibrosis can only detect up to 75% of at risk  
individuals in society. As Gostin states: “[A]pproximately one in every two couples from  
the general population identified by CF screening as ‘at-risk’ will be falsely labeled.”  
Larry Gostin, Genetic Privacy, 23 J. L. Med. Ethics 320, 323 (1995).  
6 Some have argued that specific laws to protect only genetic privacy, as opposed to  
medical privacy generally, are misguided because of this problem of definition and the  
narrow scope of the protection which would be afforded. Compare, for example,  
George Annas, Genetic Privacy: There Ought to Be a Law, 4 Tex. Rev. L. & Pol. 9  
(1999) and Mark Rothstein, Why Treating Genetic Information Separately is a Bad Idea,  
4 Tex. Rev. L. & Pol. 33 (1999).  
7 Neil Holtzman & Michael Watson, Final Report of the Task Force on Genetic Testing.:  
Promoting Safe and Effective Genetic Testing in the United States, 6 (1998).  
8 House of Commons Science and Technology Committee, Human Genetics: The Science  
and Its Consequences paragraphs 71 – 72 (Third Report, HMSO, 1995)the Report  
makes clear, “Diagnosis is aimed at individuals; genetic screening is routine screening of  
populations, or identifiable subsets of populations (for example, men or women only, or  
ethnic groups at increased risk for particular diseases).”Id.  
See also Ann Sommerville & Veronica English, Genetic Privacy: Orthodoxy or  
Oxymoron?, 25 J. Med. Ethics 144 (1999).  
10 See Graeme Laurie, The Most Personal Information of All: An Appraisal of Genetic  
Privacy in the Shadow of the Human Genome Project, 10 Int’l J.L. Pol. & Fam. 74  
(1996).  
See, Sonia Suter, Whose Genes Are These Anyway?: Familial Conflicts over Access to  
Genetic Information, 91 Mich. L. Rev. 1854, 1893 (1993).  
12 Gostin, supra note 5, at 322.  
13 The existence of this interest has been recognized by a variety of bodies, including the  
Committee on Human Genome Diversity (National Research Council), Evaluating  
Human Genetic Diversity, (National Academy of Science, Washington, DC, 1997);  
National Institutes of Health Office of Protection from Research Risks, Human Genetic  
Research, in PROTECTING HUMAN RESEARCH SUBJECTS: INSTITUTIONAL  
REVIEW BOARD GUIDEBOOK, (Washington, DC, 1993); Nuffield Council on  
Bioethics, Genetic Screening: Ethical Issues, (London, Dec. 1993), The Royal College of  
Physicians of London, Ethical Issues in Clinical Genetics: A Report of the Working  
Group of the Royal College of Physicians’ Committees on Ethical Issues in Medicine  
and Clinical Genetics, (1991), and the Danish Council of Ethics, Ethics and Mapping the  
Human Genome 62 (1993).  
14 See Somerville & English, supra note 9. See THE RIGHT TO KNOW AND THE  
RIGHT NOT TO KNOW, (Ruth Chadwick et al. eds. 1997).  
15 Because of technological advances in the last 50 years in the field of computers, the  
means now exist to store and access all forms of information for indefinite periods of  
time. In this way, genetic information could also prove relevant for future generations of  
the same genetic line. See Barry Barber, Securing Privacy in Medical Genetics, Second  
Symposium of the Council of Europe on Bioethics, Strasbourg, 30 Nov. - 2 Dec. 1993,

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- CDBI-SY-SP (93) 2 at 6, and Kåre Berg, Confidentiality Issues in Medical Genetics: The Need for Laws, Rules and Good Practices to Secure Optimal Disease Control, Second Symposium, supra at 3.
- 16 See, Jean Wilson et al., PRINCIPLES OF INTERNAL MEDICINE 30 (1991) (“as the degree of relation becomes more distant, the likelihood of a relative inheriting the same combination of genes becomes less. Moreover, the chances of any relative inheriting the right combination of genes decrease as the number of genes required for the expression of a given trait increases”).
- 17 For survey evidence from the United States and the United Kingdom of discriminatory practices in insurance that had little foundation in scientific fact, see Paul Billings et al., Discrimination as a Consequence of Genetic Testing, 50 Am. J. Hum. Gen 476 (1992); Joseph Alper et al., Genetic Discrimination and Screening for Hemochromatosis, 15 J. Pub. Health Pol. 345 (1994); Lisa Geller et al., Individual, Family and Social Dimensions of Genetic Discrimination: A Case Study Analysis, 2 Sci. Eng. Ethics 71 (1996); Lawrence Low et al., Genetic Discrimination in Life Insurance: Empirical Evidence from a Cross-sectional Survey of Genetic Support Groups in the UK, 317 Brit. Med. J. 1632 (1998).
- 18 See Mark Ryan et al., An Ethical Debate: Genetic Testing for Familial Hypertrophic Cardiomyopathy in Newborn Infants, 310 Brit. Med. J. 856 (1995); Philip Reilly, Rights, Privacy, and Genetic Screening, 64 Yale J. Bio. Med. 43 (1991).
- 19 See David Ball et al., Predictive Testing of Adults and Children in GENETIC COUNSELLING: PRACTICE AND PRINCIPLES (Angus Clarke ed. 1994) & Mary Pelias, Duty to Disclose in Medical Genetics: A Legal Perspective, 39 Am. J. Med. Gen. 347 (1991).
- 20 This having been said, in circumstances where a cure is available but an individual would not choose to take it -- for example, for religious reasons -- it is hard to see how disclosure could ever be justified because the perceived harm could not be avoided. Of course, one could argue that, faced with the reality of the situation, the individual might nevertheless accept treatment, but this is to adopt a strong paternalistic perspective, the ethical propriety of which is doubtful to many.
- 21 See Jessica Buxton & Marcus Pembrey, The New Genetics: What the Public Wants to Know, 4 Eur. J. Hum. Gen. (Suppl.) 153 (1996); Marja Hietala et al., Attitudes Towards Genetic Testing Among the General Population and Relatives of Patients with a Severe Genetic Disease: A Survey from Finland, 56 Am. J. Hum. Gen. 1493 (1995); Ball et al., supra note 19, quoting several others including, Michael Hayden, Predictive Testing for Huntington's Disease: Are We Ready for Widespread Community Implementation?, 40 Am. J. Med. Gen. 515 (1991) and Jason Brandt et al., Presymptomatic Diagnosis of Delayed-Onset with Linked DNA Markers: the Experience of Huntington's Disease, 261 J.A.M.A. 3108 (1989).
- 22 See DANIEL KEVLES, IN THE NAME OF EUGENICS: GENETICS AND THE USES OF HUMAN HEREDITY 298 (1985); Elizabeth Almqvist et al., “Risk Reversal in Predictive Testing for Huntington Disease”, 61 Am. J. Hum. Gen. 945 (1997), Joanna Fanos & John Johnson, Perception of Carrier Status by Cystic Fibrosis Siblings, 57 Am. J. Hum. Gen. 431 (1995); Lori Andrews, Legal Aspects of Genetic Information, 64 Yale J. Bio. & Med. 29 (1990); David Craufurd et al., Uptake of Presymptomatic Predictive Testing for Huntington's Disease, 2 Lancet 603 (1989).
- 23 Danish Council of Ethics supra note 13, at 60. Whereas this is arguably true of all disease, the problem can be particularly acute with genetic disease because individuals can have future ill health predicted. Thus a person can be affected even when they are perfectly healthy. With non-genetic disease usually one is actually affected by the disease before suffering psychological sequelae.
- 24 Diane Hoffman & Eric Wulfsberg, Testing Children for Genetic Predispositions: Is it in Their Best Interest?, 23 J. L. Med. & Ethics 331 (1995).
- 25 This is a genetic enzyme deficiency which is common in persons of Scandanavian descent. Those with the gene have a high risk of developing adult-onset emphysema.

26 Cystic Fibrosis results in thick secretions in the lungs and pancreas that lead to chronic  
 27 pulmonary and digestive disease.  
 28 This condition is typified by chronic muscle wasting. The disease usually manifests itself  
 in children of between two and four years of age. Death normally results by the middle  
 teenage years.  
 Hoffman and Wulfsberg cite the following articles as authority: T. Thelin et al.,  
Psychological Consequences of Neo-natal Screening for Alpha<sub>1</sub>-Antitrypsin Deficiency  
(ATD), 74 Acta Paed. Scan. 787 (1985) and T. F. McNeil et al., Psychological Effects of  
Screening for Somatic Risk : The Swedish Alpha<sub>1</sub>-Antitrypsin Experience, 43 Thorax  
 505 (1988).  
 Hoffman & Wulfsberg, supra note 24, at 333.  
 Id.  
 Kevles, supra note 22, at 298.  
 See Elizabeth Almquist et al., A Worldwide Assessment of the Frequency of Suicide,  
Suicide Attempts, or Psychiatric Hospitalization after Predictive Testing for Huntington  
Disease, 64 Am. J. Hum. Gen. 1293 (1999). The authors surveyed 100 centers in 21  
 countries and gathered data on 4,527 individuals who had undergone predictive genetic  
 testing for Huntington's disease. Of those reviewed, 1,817 people had received a positive  
 result, of whom five had taken their own lives. This extrapolates to 138/100,000 suicides  
 per year, compared to the United States average of 12-13/100,000 per year. See Thomas  
 Bird, Outrageous Fortune: The Risk of Suicide in Genetic Testing for Huntington  
Disease, 64 Am. J. Hum. Gen. 1289 (1999).  
 See Bird, supra note 32.  
 Marlene Huggins et al., Predictive Testing for Huntington Disease in Canada: Adverse  
Effects and Unexpected Results in Those Receiving a Decreased Risk, 42 Am. J. Med.  
 Gen. 508 (1992).  
 Nancy Wexler, Genetic Jeopardy and the New Clairvoyance, 6 Progress Med. Gen. 277  
 (1985).  
 Id.  
 In one study, only 43% of women tested for BRCA1 wanted to know the result. See  
 Caryn Lerman et al., BRCA1 Testing in Families with Hereditary Breast-Ovarian Cancer,  
 275 J.A.M.A. 1885, 1888 (1996).  
 This declaration was adopted at the World Medical Association's 44th assembly in 1992.  
 This point is made particularly well by the Danish Council of Ethics, supra note 13, at  
 52.  
 These four principles typify the model of bioethics developed by THOMAS  
 BEAUCHAMP & JAMES CHILDRESS, PRINCIPLES OF BIOMEDICAL ETHICS  
 (4th ed. 1994). This is not the only model of medical ethics in existence, but is the one  
 preferred by the present writer.  
 This term is borrowed from Stanley Benn, *inter alia*, from his work, *A Theory of*  
*Freedom* (1988).  
 For example, the United Kingdom Advisory Committee on Genetic Testing (ACGT)  
 has issued a Code of Practice that recommends strongly that over the counter test kits  
 should only be made available in respect of carrier status, and not for more severe  
 conditions such as late-onset Huntington's disease or X-linked disorders. The rationale  
 is that while the discovery of carrier status has no direct implications for a proband's  
 health, the discovery of a fatal condition such as Huntington's disease should not occur  
 outside the clinical setting where full and appropriate counseling can be provided:  
 ACGT, Code of Practice for Genetic Testing Offered Commercially Direct to the Public  
 (London, Dep't of Health 1997).  
 The gene contains around 100,000 base pairs of nucleotides. It was discovered on  
 September 15, 1994, by a team of researchers at the University of Utah.  
 Tamoxifen has been used in the treatment of breast cancer for over two decades, but its  
 preventative efficacy remains unknown. See Susan Nayfield et al., Potential Role of  
Tamoxifen in Prevention of Breast Cancer, 83 J. Nat. Cancer Inst. 1450 (1991).



45 This point is cogently made by GERALD DWORKIN, *THE THEORY AND*  
*PRACTICE OF AUTONOMY* 5-6 (1988).

46 See, e.g., JOEL FEINBERG, *HARM TO SELF* 54 (1986); ISAIAH BERLIN, *FOUR*  
*ESSAYS ON LIBERTY* 131 (1969), DWORKIN, *supra* note 45, at 20; JOSEPH RAZ,  
*THE MORALITY OF FREEDOM* 370-72 (1986); Joseph Raz, *Autonomy, Toleration,*  
*and the Harm Principle* in *ISSUES IN LEGAL PHILOSOPHY* 313-33 (Ruth Gavison

47 ed. 1987); and BEAUCHAMP & CHILDRESS, *supra* note 40, at 121.

48 See BEAUCHAMP & CHILDRESS, *supra* note 40, at 121 - 22; BERLIN, *supra* note  
 46, at 131; DWORKIN, *supra* note 45, at 18, 19; and RAZ, *supra* note 46, at 408 - 11.

49 On capacity, see DWORKIN, *supra* note 45, at 20; RAZ, *supra* note 46, at 408; Raz,  
*supra* note 46, at 314; BEAUCHAMP & CHILDRESS, *supra* note 40, at 132 - 41

50 See Raz, *supra* note 46, at 314.

51 This point is made by BEAUCHAMP & CHILDRESS, *supra* note 40, at 123.

52 The classic pronouncement by Justice Cardozo in *Schloendorff v. Society of New York*  
*Hospital*, 211 NY 125, 105 NE 92 (1914) scarcely requires repetition: "Every human  
 being of adult years and sound mind has a right to determine what shall be done with his  
 body..."

53 BEAUCHAMP & CHILDRESS, *supra* note 40, at 126.

54 See Dorothy Wertz & John Fletcher, *Privacy and Disclosure in Medical Genetics*  
*Examined in an Ethic of Care*, 5 *Bioethics* 212, 221 (1991).

55 See Roberta Berry, *The Genetic Revolution and the Physician's Duty of Confidentiality*,  
 18 *J. Leg. Med.* 401, 435 - 36 (1997).

56 See JAY KATZ, *THE SILENT WORLD OF DOCTOR AND PATIENT* 141 (1984)  
 who argues that "[t]he inevitable conflict that such insistence [on disclosure and  
 conversation] creates between the values of autonomy and privacy should be resolved in  
 favour of autonomy. Such invasions of privacy must be tolerated in order to enhance  
 patients' psychological autonomy through insight and not allow it to be further  
 undermined by too hopeful promises, blind misconceptions and false certainties."

57 Bruce Charlton, *Screening Ethics and the Law*, 305 *Brit. Med. J.* 521 (1992).

58 Heidi Malm, *Medical Screening and the Value of Early Detection: When Unwarranted*  
*Faith Leads to Unethical Recommendations*, 21 *Hastings Center Rep.* 26, 36 (1999).

59 Information that is in the public domain cannot be confidential and therefore cannot be  
 protected by confidentiality. Similarly, once information moves from the private sphere  
 where it is confidential to the public sphere, it loses the necessary quality of confidence.

60 See, e.g., *Alberts v. Devine*, 479 N.E.2d 113 (Mass. 1985); *Bryson v. Tillinghast*, 749  
 P.2d 110 (Okla. 1988); *People v. Doe*, 435 N.Y.S.2d 656 (Sup. Ct. 1981).

61 For example, in *Hague v. Williams*, 181 A. 2d. 345, 349 (1963) it was stated: "[A]lthough  
 ordinarily a physician receives information relating to a patient's health in a confidential  
 capacity....where the public interest or the private interest of the patient so  
 demands,...disclosure may,under...compelling circumstances, be made to a person with a  
 legitimate interest in the patient's health."

62 See, e.g., *Horne v. Paton*, 287 So. 2d 824 (Ala. 1973); *McDonald v. Clinger*, 446 N.Y.S.  
 2d 801 (1982); *In re Lasswell*, 673 P.2d 855 (Or. 1983). Cf. *Logan v. District of*  
*Columbia*, 447 F. Supp. 1328 (D.D.C. 1978); *Quarles v. Sutherland*, 389 S.W. 2d. 249  
 (1965). For the statutory legal position as of 1996, see LARRY GOSTIN et al.,  
*LEGISLATIVE SURVEY OF STATE CONFIDENTIALITY LAWS, WITH*  
*SPECIAL EMPHASIS ON HIV AND IMMIGRATION* (1996); J. SAUNDERS,  
*PATIENT CONFIDENTIALITY* 56-67 (1996). For the common law position, see  
 Judy Zelin, *Annotation: Physicians Tort Liability for Unauthorised Disclosure of*  
*Confidential Information*, 48 A.L.R. 4th 668 (1998).

63 Principle IV of the American Medical Association Code of Medical Ethics states: "A  
 physician shall respect the rights of patients, of colleagues, and of other health  
 professionals, and shall safeguard patient confidences within the constraints of the law."  
 See also, Council on Ethical and Judicial Affairs, *Fundamental Elements of the Patient-*  
*Physician Relationship*, 264 J.A.M.A. 3133 (1990): "The patient has the right to

confidentiality. The physician should not reveal confidential communications or information without the consent of the patient, unless provided for by the law or by the need to protect the welfare of the individual or the public interest.”

63 Of the numerous versions of the Hippocratic Oath that are available, the following passage is typical in respect of the obligation to maintain confidences: “[A]ll that may come to my knowledge in the exercise of my profession or outside of my profession or in daily commerce with men, which ought not to be spread abroad, I will keep secret and will never reveal.” See Berry, supra note 54, at 408 – 13, for an overview of the history of the Hippocratic Oath.

64 For an account, see William ROACH, Jr., MEDICAL RECORDS AND THE LAW 91ff (3rd ed. 1998).

65 See Note, Breach of Confidence: An Emerging Tort, 82 Columbia Law Rev. 1426 (1982).

66 In *Quarles v. Sutherland*, 389 S.W. 2d 249 (Tenn. 1965) the provision of free medical treatment meant that no contractual duty arose between physician and patient, and so no duty of confidentiality. In *Macdonald v. Clinger*, 446 N.Y.S. 2d 801 (N.Y. App. 1982) the court stated: “We believe that the relationship contemplates an additional duty springing from but extraneous to the contract that the breach of such duty is actionable as a tort.” This is a fiduciary relationship arising from the contractual nature of the relationship. *Hammonds v. Aetna Cas. and Sur. Co.*, 243 F. Supp. 793 (N.D. Ohio 1965).

67 In *Darnell v. Indiana*, 674 N.E. 2d 19 (Ind., 1996) a physician-patient privilege statute was construed narrowly to exclude nurses from the duty of confidentiality; similarly in *Evans v. Rite Aid Corp.*, 478 S.E. 2d 846 (S.C. 1996) and *Suarez v. Pierard*, 663 N.E. 2d 1039 (Ill. App. 1996) pharmacists were held to have no duty in the absence of a contractual obligation.

68 This would be the case in other jurisdictions, such as those of the United Kingdom, where a duty of confidence can arise provided that a reasonable person would realize, or should have realized, that he or she was receiving information in circumstances that imported a duty of confidence, see *Attorney General v. Guardian Newspapers*, (No.2) [1990] AC 109; *Lord Advocate v. Scotsman Pub. Ltd.*, 1989 SLT 705; *Stephens v. Avery* [1988] Ch 449.

69 Indeed, the Committee on Genetic Risks of the Institute of Medicine has gone even further and has suggested that an obligation of disclosure to relatives should be imposed in certain circumstances:

The Committee recommends that confidentiality be breached and relatives informed about genetic risks only when attempt to elicit voluntary disclosure fail, there is a high probability of irreversible or fatal harm to the relative, the disclosure of the information will prevent harm, the disclosure is limited to the information necessary for diagnosis or treatment of the relative, and there is no other reasonable way to avert the harm.

Assessing Genetic Risks, Implications for Health and Social Policy 278 (Lori Andrews et al. eds. 1994). Similarly, see President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, Screening and Counseling for Genetic Conditions (1983).

70 CHARLES FRIED, AN ANATOMY OF VALUES: PROBLEMS OF PERSONAL AND SOCIAL CHOICE 142 (1970).

71 JULIE INNESS, PRIVACY, INTIMACY AND ISOLATION (1992).

72 Sidney Jouard, Some Psychological Aspects of Privacy, 31 Law & Contemp. Probs. 307 (1966). See also, PETER PETSCHAUER, HUMAN SPACE: PERSONAL RIGHTS IN A THREATENING WORLD (1997).

73 See Stanley Benn, Privacy, Freedom and Respect for Persons, in PHILOSOPHICAL DIMENSIONS OF PRIVACY: AN ANTHOLOGY 230-31 (Ferdinand Schoeman ed. 1984).

74 Kent Greenawalt, Privacy and Its Legal Protections, 2 Hastings Cent. Studies 45 (1974).

75 Benn, supra note 73, at 237, observes that,  
the children of the kibbutz have been found by some observers defective as  
persons, precisely because their emotional stability has been purchased at the  
cost of an incapacity to establish deep personal relations. Perhaps we have to  
choose between the sensitive, human understanding that we achieve only by the  
cultivation of our relations within a confined circle and the extrovert assurance  
and adjustment that a Gemeinschaft can offer. However this may be, to the extent  
that we value the former, we shall be committed to valuing the right of privacy.

76 The Supreme Court has expressly recognized the importance of the public and private  
interests in protecting the confidential nature of the therapeutic alliance (most  
particularly in the context of the psychotherapeutic relationship). See Jaffee v. Redmond,  
518 U.S. 1 (1996).

77 See, e.g., the Electronic Privacy Information Center survey list at  
<http://www.epic.org/privacy/survey/>. See also, RAYMOND WACKS, PERSONAL  
INFORMATION, PRIVACY AND THE LAW (1989).

78 This notion can of course extend to the privacy of groups that are apart from other  
groups or society in general, but the common denominator is the individual and his or  
her separateness.

79 Consider the position of the prisoner condemned to solitary confinement. The prisoner  
has been removed from a social context (not simply society in general but also the  
community of the prison population) and has been placed in isolation. Such a person  
does not have privacy. But, a prisoner who retires to the cell to read does have privacy in  
that the prisoner is separate from the rest of the prison community.

80 Of course, mere jostling or accidental contact is subject to the de minimis principle and  
can be explained by the implied consent of the individual who is in a public setting.

81 Indeed, one could say precisely the same about bodily contact and spatial privacy  
interests in a public crowd.

82 This is not to say that strong counterarguments cannot be made to justify such  
observation -- for example, close circuit television in shopping malls for security  
purposes. However, if such tapes are sold to television shows for entertainment  
purposes, then arguably this becomes an offensive use of the images obtained.

83 Samuel Warren & Louis Brandeis, The Right to Privacy 4 Harv. Law Rev. 193 (1890-91).

84 For a seminal analysis, see Dean Prosser, Privacy: A Legal Analysis 48 Cal. L. Rev. 338  
(1960).

85 Warren & Brandeis, supra note 83, at 205.

86 See, e.g., Abernathy v. Hutchinson, 3 L. J. Ch. 209 (1825); Prince Albert v. Strange, 1  
McN. & G. 25 (1849).

87 For example, Tuck v. Priester, 19 QBD 639 (1887).

88 It is often pointed out that, ironically, the authors relied heavily on English common-  
law cases to support their argument and yet, to this day, no common law right to privacy  
has been recognized in England. Indeed, the English courts specifically have ruled out  
the possibility of a common law right of privacy. See Kaye v. Robertson, [1991] Fleet  
Street Rep. 62.

89 The "right to be alone" was first expounded in JUSTICE COOLEY, A TREATISE ON  
THE LAW OF TORTS 29 (2d ed. 1888).

90 For example, see Ruth Gavison, Too Early for a Requiem: Warren and Brandeis Were  
Right on Privacy vs. Free Speech, 43 South Carolina L. Rev. 437 (1992).

91 For example, Diane Zimmerman, Requiem for a Heavyweight: A Farewell to Warren  
and Brandeis' Privacy Tort, 68 Cornell L. Rev. 291 (1984); Walter Pratt, The Warren and  
Brandeis Argument for a Right to Privacy, Pub. L. 161 (1975); Edward Bloustein,  
Privacy, Tort Law and the Constitution: Is Warren and Brandeis' Tort Petty and  
Unconstitutional as Well?, 46 Texas L. Rev. 611 (1968); Harry Kalven, Privacy in Tort  
Law: Were Warren and Brandeis Wrong?, 31 Law & Contemp. Probs. 326 (1966).

92 See, e.g., Louis Blom-Cooper, The Right to Be Let Alone, 10 J. Media L. & Prac. 53  
(1989).

93 Charles Fried, Privacy, 77 Yale L.J. 475, 490 (1968).

94 Richard Posner, An Economic Theory of Privacy, in PHILOSOPHICAL  
DIMENSIONS OF PRIVACY: AN ANTHOLOGY, supra note 73, at 274 - 75.

95 For specific accounts in the health care context, see ROACH, supra note 64, and  
JONATHAN TOMES, HEALTHCARE PRIVACY AND CONFIDENTIALITY:  
THE COMPLETE LEGAL GUIDE (1994).

96 Louis Henkin, Privacy and Autonomy, 74 Columbia L. Rev. 1410 (1974) has argued that  
Griswold and its progeny have given rise to “an additional zone of autonomy of  
presumptive immunity to governmental regulation.” This Constitutional right of privacy  
he considers, “may not add much protection to “traditional value privacy.”, at Id. 1424 -  
25. A similar criticism has been advanced by Herman Gross, Privacy and Autonomy, in  
PHILOSOPHY OF LAW 246-51 (Joel Feinberg & Herman Gross eds. 2d ed. 1980).

97 381 U.S. 479 (1965). For an account of the historical precursor to this case and its  
impact on privacy rights, see Jed Rubenfeld, The Right of Privacy, 102 Harv. L. Rev. 737  
(1989).

98 William Parent, Privacy, Morality and the Law, 12 Phil. & Pub. Aff. 269, 274 - 5 (1983).  
Emphasis added. This is Parent’s definition of privacy.

99 Id. at 284.

100 Judith Wagner DeCew, The Scope of Privacy in Law and Ethics, 5 Law & Phil. 145, 162  
(1986).

101 Id. at 161.

102 Id. at 162. More recently, and more generally, see JUDITH WAGNER DECEW, IN  
PURSUIT OF PRIVACY: LAW, ETHICS AND THE RISE OF TECHNOLOGY  
(1997) (especially chapter 7).

103 Paris Adult Theatre I v. Slaton, 413 U.S. 49 (1973). See also, Washington v. Glucksberg,  
521 U.S. 702 (1997); Vacco v. Quill, 521 U.S. 793 (1997) (assisted suicide cases).

104 DeCew, supra note 100, at 164 - 65.

105 Id. at 165.

106 BEAUCHAMP & CHILDRESS, supra note 40, at 120 - 21.

107 DWORKIN, supra note 45

108 BERLIN, supra note 46, at 121.

109 This is supported by Robert Hallborg, Principles of Liberty and the Right to Privacy, 5  
Law & Phil. 175 (1986) who argues for a view of privacy that is deduced from  
fundamental principles of liberty. This he does “to obtain a right to privacy which is not  
easily defeasible, and a right which ought to be a permanent part of our legal system.”

110 Greenawalt has argued, for example, that “[g]iven a society in which many life-styles and  
points of view evoke negative reactions if publicly known, a substantial degree of freedom  
from observation is essential if there is to be any genuine autonomy; and real choice also  
depends on the ability of persons to enjoy states of privacy without intrusion.” RIGHTS  
OF PRIVACY 199 (John Shattuck ed. 1977) The original version of this material may be  
found at Kent Greenawalt, supra note 74.

111 Ruth Gavison, Privacy and the Limits of the Law, 89 Yale L. J. 421, 428 (1980).

112 See, e.g., Bowers v. Hardwick, 478 U.S. 186 (1986). For trenchant criticism of the case,  
see Kendall Thomas, Beyond the Privacy Principle, 92 Columbia L. Rev. 1431 (1992)  
and Mark Kohler, History, Homosexuality and Homophobia: The Judicial Intolerance of  
Bowers v Hardwick, 19 Conn. L. Rev. 129 (1986).

113 See, for example, Cruzan v. Director, Missouri Department of Health 110 S Ct 2841  
(1990) and Planned Parenthood of SE Pennsylvania v. Casey 112 S Ct 2791 (1992).

114 Supra section V.B.

115 See Prosser, supra note 84. The four privacy rights are (a) appropriation of an  
individual’s name or likeness, (b) unreasonable intrusion upon the seclusion of another,  
(c) public disclosure of private facts, and (d) subjecting an individual to publicity that  
casts them in a false light in the public’s eye.

116 See Doe v. Mills, 536 N.W. 2d 824 (1995) in which the Michigan Court of Appeals made  
it clear that the tort is constituted when secret and private subject matter is obtained by  
117 means that would be objectionable to a reasonable person.  
118 Sutherland v. Kroger Co., 110 S. E. 2d 716 (W. Va. 1959).  
119 Ford Motor Co. v. Williams, 134 S. E. 2d 483 (Ga. 1963).  
120 Rhodes v. Graham, 37 S.W. 2d 46 (Ky. 1931); McDaniel v. Atlanta Coca-Cola Bottling  
121 Co., 2 SE 2d 810 (Ga. 1939).  
122 Carey v. Statewide Finance Co., 223 A. 2d 405 (Conn. Cir. 1966).  
Public disclosure is not, however, a prerequisite. See Cort v. Bristol-Myers Co., 431 N.E.  
2d 908 (Mass. 1982); Themo v. New England Newspaper Publishing Co., 27 N.E. 2d  
753 (Mass. 1940).  
122 Ruth Macklin, Privacy and Control of Genetic Information, in GENE MAPPING:  
USING LAW AND ETHICS AS GUIDES 164 (George Annas & Sherman Elias eds.  
1992).  
123 Paul Lombardo, Genetic Confidentiality: What's the Big Secret?, 3 U. Chi. L. Sch.  
Roundtable 589, 593 (1996) (suggesting that so many exceptions have been made to  
confidentiality over the years that it has now been rendered meaningless and outlived its  
124 usefulness).  
See, e.g., Bradshaw v. Daniel, 854 S.W.2d 865 (Tenn. 1993); DiMarco v. Lynch Homes-  
Chester County, 559 A.2d 530, *aff'd* 583 A.2d 422 (Pa. 1990); Shepard v. Redford  
Comm. Hosp., 390 N.W.2d 239 (Mich. 1986); Gooden v. Tips, 651 S.W.2d 364 (Tex.  
1983); Bradley Ctr. V. Wessner, 287 S.E.2d 716 (Ga. 1982); McIntosh v. Milano, 403  
A.2d 500 (N.J. 1979); Renslow v. Mennonite Hosp., 367 N. E. 2d 1250 (Ill. 1977);  
Tarasoff v. Regents of Univ. of Cal., 551 P.2d 334 (Cal. 1976); Hofmann v. Blackmon,  
241 So. 2d 752 (Fla. 1970).  
125 661 So. 2d 278 (Fla. 1995).  
126 In Schroeder v. Perkel, 432 A. 2d 834 (N. J. 1981) the court recognized a duty of a  
physician to the parents of a child whose cystic fibrosis had not been correctly diagnosed  
to inform the parents of the child's condition. The court said:  
The foreseeability of injury to members of a family other than one immediately  
injured by the wrongdoing of another must be viewed in light of the legal  
relationships among family members. A family is woven of the fibers of life; if  
one strand is damaged, the whole structure may suffer. The filaments of family  
life, although individually spun, create a web of interconnected legal interests.  
Id. at 63-64.  
127 Pate, 661 So. 2d at 282. An analogous decision in the context of HIV infection is  
Reisner v. The Regents of the Univ. of Cal., 37 Cal. Rptr. 2d 518 (Cal., 1995).  
128 677 A.2d 1188 (N.J. 1996).  
129 Id. at 1192-93.  
130 Id.  
131 It is by no means certain that it will be followed. See, e.g., Olson v. Children's Home  
Soc'y of California, 252 Cal. Rptr. 11 (Cal. 1988); Ellis v. Peter, 627 N.Y.S.2d 707 (N.Y.  
App. 1995); Conboy v. Mogeloff, 78 N.Y. 2d 862 (N.Y. App. 1991); Sorgente v.  
Richmond Mem. Hosp., 539 N.Y.S.2d 269 (N.Y. Supreme 1989).  
132 For an interesting attitudinal survey about the responsibility of patients and genetic  
services providers to remain in contact, see Jennifer Fitzpatrick et al., The Duty to  
Recontact: Attitudes of Genetics Service Providers, 64 Am. J. Hum. Gen. 852 (1999).  
133 Lori Andrews, Torts and the Double Helix: Malpractice Liability for Failure to Warn of  
Genetic Risks, 29 Hous. L. Rev. 149, 181 (1992) (recognition of a duty of disclosure to  
relatives with whom a physician has no direct professional relationship should, logically,  
also give rise to a duty for physicians to tell strangers of the health risks that they run).  
134 See also, Graeme Laurie, Obligations Arising from Genetic Information -- Negligence  
and the Protection of Familial Interests, 11 Child & Fam. L.Q. 109 (1999).  
135 While the tort of intentional infliction of emotional distress might initially appear  
helpful, the requirement that there be evidence of intention to cause harm through

extreme and outrageous conduct, as judged from the perspective of the reasonable person is unlikely ever to be met in circumstances such as those under discussion, which deal with nuanced matters of professional and individual judgement: see, for example, *Harris v. Jones*, 380 A.2d 611 (Md. 1977).

136 See Dorothy Wertz, Legislative Update: Genetic Privacy Bills, 3 The Gene Letter Feb. (1999) (<http://www.geneletter.org/0299/legislativeupdate.htm>). For comment, see Jeremy Colby, An Analysis of Genetic Discrimination Legislation Proposed by the 105th Congress, 24 Am. J. L. & Med. 443 (1998).

137 By January 1999 44 states had introduced laws concerning genetic privacy or discrimination, see William Mulholland & Ami Jaeger, Genetic Privacy and Discrimination: A Survey of State Legislation, 40 Jurimetrics 317 (1999).

138 Paul Starr, Health and the Right to Privacy, 25 Am. J. L. & Med. 193 (1999).

139 Cf. Tony McGleenan, Rights to Know and Not to Know: Is There a Need for a Genetic Privacy Act?, in THE RIGHT TO KNOW, *supra* note 14.

140 For information on this see, Human Genome News, 6 March - April 1995, at 4.

141 The text of the Act can be found at: <[http://www.ornl.gov/TechResources/Human\\_Genome/resource/privacy/privacy1.html](http://www.ornl.gov/TechResources/Human_Genome/resource/privacy/privacy1.html)>. It would seem that the most far-reaching legislation has been passed in New Jersey. For comment, see Fred Charatan, New Jersey Passes Genetic Privacy Bill, 313 Brit. Med. J. 71 (1996). In Maryland a bill based on the GPA was defeated in the state Senate. For comment, see Neil Holtzman, Panel Comment: The Attempt to Pass the Genetic Privacy Act in Maryland, 23 J. L. Med. & Ethics 367 (1995).

142 Genetic Privacy Act (GPA), s.3 For the text of this section see [http://www.bumc.bu.edu/www/sph/lw/gpa/GPA\\_cmld.htm](http://www.bumc.bu.edu/www/sph/lw/gpa/GPA_cmld.htm)

143 *Id.* §104(a). This move clearly has very far-reaching implications for a great number of areas within the disciplines of law, medicine, and science generally. These are, however, outside the scope of this article. For comment see, Micahel Lin, Conferring a Federal Property Right in Genetic Material: Stepping into the Future with the Genetic Privacy Act, 22 Am. J. L. & Med. 109 (1996).

144 Part A of the Act deals with collection and analysis of DNA samples; Part B concerns disclosure of private genetic information.

145 See Part B of the Act which is concerned with matters of consent and disclosure.

146 GPA §101(b)(8).

147 See also George Annas et al., Drafting the Genetic Privacy Act: Science, Policy, and Practical Considerations, 23 J. L. Med. & Ethics 360 (1995). For a critique see Edwin Troy, The Genetic Privacy Act: An Analysis of Privacy and Research Concerns, 25 J. L. Med. & Ethics 256 (1997).

148 The Genetic Privacy Act and Commentary (1995) is available on request from the Health Law Department, Boston University School of Public Health, 80 East Concord Street, Boston, MA 02118 and also on the Department's web site at: <http://www.bumc.bu.edu/sph/internet.htm>

149 The GPA does not go so far as to recognize any spatial privacy interests for fetuses. Sections 151 and 152 provide that a competent pregnant woman has the sole right to determine both when DNA samples shall be taken from her fetus and how genetic information about the fetus shall be used.

150 GPA, §101(b). The GPA requires, among other things, that the sample source be told: (1) that consent to the collection and taking of the DNA sample, and its analysis, is voluntary; (2) about the information that reasonably can be derived from the analysis; (3) that the genetic analysis may result in information about the sample source's genetic relatives, which may not be known to such relatives but could be important, and if so the sample source will have to decide whether or not to share that information with relatives; and (4) about the existence of genetic counseling.

151 See Malm, *supra* note 57.

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- 152 Madison Powers, Privacy and the Control of Genetic Information, in THE GENETIC  
FRONTIER: ETHICS, LAW AND POLICY 82 (Mark Frankel & Albert Teich eds.  
1994).
- 153 The Secretary of Health and Human Services recommended five guidelines in 1997 to  
shape the future of health privacy laws. Among these was the principle of “public  
responsibility” which states that: “individuals’ claims to privacy must be balanced by  
their public responsibility to contribute to the public good through use of their  
information for important socially useful purposes, with the understanding that their  
information will be used with respect and care and will be legally protected.” See  
Confidentiality of Individually-identifiable Health Information: Recommendation of the  
Secretary of Health and Human Services, Pursuant to Section 264 of the Health  
Insurance Portability and Accountability Act 1996, September 1997.  
<http://aspe.os.dhhs.gov/admsimp/PVCREC1.htm>.
- 154 But, the security of the samples taken from such infants deserve no less stringent  
security measures for having been the source of valuable medical interventions, see  
generally, STORED TISSUE SAMPLES: ETHICAL, LEGAL AND PUBLIC POLICY  
IMPLICATIONS (Robert Weir ed. 1998) (especially chapter 1).
- 155 Note, however, that Ruth Chadwick has pointed out that the concept of solidarity can  
be invoked to justify a claim that families do have a collective claim concerning the use  
and control of their genetic information. See Ruth Chadwick, The Philosophy of the  
Right to Know and the Right Not to Know in THE RIGHT TO KNOW, *supra* note  
14, at 20.
- 156 Cf. AMITAI ETZIONI, THE LIMITS OF PRIVACY (1999), Morris Foster et al., The  
Role of Community Review in Evaluating the Risks of Human Genetic Variation  
Research, 64 Am J. Hum. Gen. 1719 (1999); and Helena Rubinstein, If I Am Only for  
Myself, What Am I? A Communitarian Look at the Privacy Stalemate, 25 Am. J. L. &  
Med. 203 (1999).
- 157 The Bilbao Declaration on the Human Genome was drafted at the International  
Workshop on Legal Aspects of the Human Genome Project, which took place in Bilbao,  
Spain in May of 1993.
- 158 Council of Europe, Convention for the Protection of Human Rights and Dignity of the  
Human Being with Regard to the Application of Biology and Medicine: Convention on  
Human Rights and Medicine (Oviedo, Apr. 1997) (emphasis added).
- 159 Adopted unanimously on November 11 1997 in Paris at the Organization’s 29th  
General Conference (emphasis added).